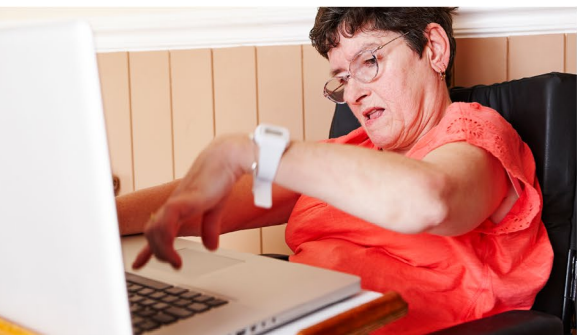




Department of Defense



Guide for Adults with Special Needs



Table of Contents

i

Module 1: Introduction

Introduction to Module 1	1:1
Who Are Adults with Special Needs?	1:1
<i>The Adult Child with Special Needs</i>	1:1
<i>The Adult with an Acquired Special Need</i>	1:2
<i>The Caregiver</i>	1:2
Themes	1:2
<i>Equal Opportunity</i>	1:2
<i>Independent Living</i>	1:2
<i>Community Participation</i>	1:3
<i>Economic Self-Sufficiency</i>	1:3

Module 2: Military Resources and Support

Introduction to Module 2	2:1
Family Centers	2:1
<i>Exceptional Family Member Program</i>	2:2
<i>Relocation Assistance Program</i>	2:2
<i>Deployment Support Program</i>	2:3
<i>Personal Financial Management Program</i>	2:3
<i>Family Advocacy Program</i>	2:3
Other Support Services	2:4
Relief Societies	2:4
Service-Sponsored Websites	2:5
Additional Military Resources	2:5
<i>Military OneSource's EFMP Section</i>	2:5
<i>Plan My Move</i>	2:6
<i>MilitaryINSTALLATIONS</i>	2:6

Module 3: TRICARE® Health Benefits

Introduction to Module 3	3:1
TRICARE® Options for Active Duty Family Members	3:2
<i>TRICARE® Prime</i>	3:2
<i>TRICARE® Prime Remote</i>	3:3
<i>TRICARE® Standard</i>	3:3

TRICARE® Extra	3:4
TRICARE® after Retirement	3:4
Supplemental Health Insurance for Retirees	3:4
Pharmacy Benefit	3:4
TRICARE® Benefits for Families with Special Needs	3:5
Case Management	3:5
Mental Health Care	3:5
Hospice Care	3:5
Extended Care Health Option (ECHO).....	3:5
TRICARE® Help and Information	3:8
TRICARE® Service Centers	3:9
Beneficiary Counseling and Assistance Coordinators/ Health Benefits Advisors	3:9
Debt Collection Assistance	3:9

Module 4: Equal Opportunity

Introduction to Module 4	4:1
Laws and Rights	4:1
Individuals with Disabilities Education Act	4:1
Americans with Disabilities Act.....	4:2
Section 504 of the Rehabilitation Act of 1973.....	4:2
Section 508 of the Rehabilitation Act of 1973	4:2
Understanding Systems	4:5
The Mechanics of Effective Advocacy.....	4:6
Positive Advocacy Strategies	4:6
Obtaining Needed Services	4:8
Barriers.....	4:8
When Services or Situations Are Not Ideal	4:10
Building Partnerships.....	4:10
Finding Resources and Support	4:10
Support Groups.....	4:11
Resource Centers and Networks	4:11
Community-Based Services.....	4:12

Module 5: Independent Living

Introduction to Module 5	5:1
Independent Living Options	5:1
<i>Housing Assistance Programs</i>	5:1
<i>Home-Based Services</i>	5:3
<i>Home Modifications and Assistive Technology</i>	5:5
<i>Supported Living Arrangements</i>	5:8
<i>Residential Placements</i>	5:9
Well-Being	5:10
<i>Personal Well-Being</i>	5:11
<i>Compassion Fatigue</i>	5:12
<i>Counseling Services</i>	5:13
<i>Military OneSource</i>	5:13
Personal Safety	5:13
Emergency Preparedness	5:14
<i>Emergency Response Systems</i>	5:14
<i>Emergency Services</i>	5:15
<i>Service Animals</i>	5:15
<i>Military Aid Societies</i>	5:15
Transportation	5:16

Module 6: Community Participation

Introduction to Module 6	6:1
Finding the Right Activity	6:1
<i>Parks and Recreation Activities</i>	6:1
<i>Athletic and Sports Programs</i>	6:2
<i>Hobbies and Crafts</i>	6:2
<i>Art Programs</i>	6:2
<i>Travel</i>	6:2
<i>Volunteer Programs</i>	6:3
<i>Religious and Spiritual Programs</i>	6:3
<i>Fraternal Organizations</i>	6:3
<i>Disability-Specific Organizations</i>	6:3

Module 7: Economic Self-Sufficiency

Introduction to Module 7	7:1
Educational Options	7:1
<i>Educational Paths</i>	7:1
Employment	7:6
<i>The Americans with Disabilities Act</i>	7:6
<i>Community-Based Employment Options</i>	7:7
<i>Employment Assistance</i>	7:9
Financial Assistance	7:11
<i>Supplemental Security Income</i>	7:12
<i>Social Security Disability Insurance</i>	7:12
<i>Supplemental Nutrition Assistance Program</i>	7:13
<i>Health Care Assistance</i>	7:13

Module 8: Legal and Financial Issues

Introduction to Module 8	8:1
Why Planning is Important	8:1
<i>Special Care Organizational Record</i>	8:1
<i>Installation Legal Assistance Office</i>	8:2
<i>Estate Planning</i>	8:2
<i>Letters of Intent</i>	8:2
<i>Wills</i>	8:3
<i>Powers of Attorney</i>	8:3
<i>Advance Health Care Directives</i>	8:4
<i>Special Needs Trusts</i>	8:4
<i>Guardianship and Conservatorship</i>	8:5
<i>End-of-Life Care</i>	8:8

Module 9: Moving Ahead

Introduction to Module 9	9:1
The Exceptional Family Member Program	9:2
<i>Enrollment</i>	9:2
<i>Benefits of Assignment Coordination</i>	9:3

EFMP Family Support	9:3
Relocation	9:4
Overseas Screening	9:5
Living Overseas While Managing a Special Need	9:6
Building Resilience	9:6

Addendum

Educational Paths	A:1
High School Opportunities for Trade and Career Technical Education	A:1
Other High School Program Options	A:1
High School/High Tech Program	A:2
Project SEARCH	A:2
Start on Success	A:2
Final Care	A:3
Home Care Provider Considerations	A:4
Legal Process	A:6
Life Domains	A:7
Personal Responsibility and Relationships	A:8
Home and Family	A:8
Education and Employment	A:9
Physical and Emotional Health	A:9
Community Involvement	A:9
Recreation and Leisure	A:9
Safety and Accident Prevention	A:10

Throughout this guide the reader will be directed to Military OneSource:

- website: www.militaryonesource.mil
- toll free number: 1 (800) 342-9647.

Many of the materials, applications and resources are available on the website, or can be ordered via the toll free number. In all cases, Military OneSource will be indicated.



Notes

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Introduction

Introduction to Module 1

The Department of Defense (DoD) Guide for Adults with Special Needs provides information and resources to address a wide range of topics related to the concerns of adults with special needs, whether they are adult children, adults diagnosed with a condition or disability, or caregivers. Some sections of this guide are relevant to adult children with a disability while other information may be more appropriate to adults diagnosed with a medical condition. This guide is also intended for use by caregivers. Caregivers, whether family members or professionals, support an individual by providing personal care, household management, assistance with decision making, or acting as an advocate.

Who Are Adults with Special Needs?

Adults with special needs are individuals over the age of eighteen who have a medical condition or a diagnosed developmental disability. This could be a spouse with a chronic illness or an acquired disability, a child with a developmental disorder transitioning to adulthood, or a family member over twenty-one with severe special needs who is unable to live on his/her own. For the purpose of this guide, these individuals are also:

- members of a military family
- registered in the Defense Enrollment Eligibility Reporting System (DEERS) (www.tricare.mil—search "DEERS")
- eligible for enrollment in the Exceptional Family Member Program (EFMP)

The Adult Child with Special Needs

Sections of this guide provide information pertinent to the young adult with special needs who is receiving services through an Individualized Education Program (IEP) and who requires transition support upon reaching the age of majority or has transitioned to adult services. This also includes those who remain under guardianship or incapacitated adult status.



Introduction

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This is a companion guide to the DoD Special Needs Parent Tool Kit, which is designed to assist military families who have children with special needs. It is available for download at www.militaryonesource.mil/efmp/parent-tool-kit or can be ordered from Military OneSource.

The Adult with an Acquired Special Need

Sections of this guide include information specific to the individual diagnosed with an illness or a disability after reaching adulthood. Often, resources available for managing an adult-onset special need are the same as those provided for lifelong disabilities. This guide offers information pertinent to adult-onset conditions with additional links to other resources.

The Caregiver

Sections of this guide provide information and resources helpful to a caregiver. This person may be a spouse, parent, other family member, friend, or professional. Providing support for someone with disabilities varies depending on the individual's condition and the caregiver. This guide will help the caregiver support the individual with a disability in accessing resources and information. It will also provide caregivers with insights and ideas for taking care of themselves.



Themes

Several themes have emerged from federal laws, related to equal rights and disabilities. The laws are described in Module 4, [Equal Opportunity](#). This guide uses the following themes to frame the information and resources to assist adults with special needs and their caregivers in setting goals and planning for the future.

Equal Opportunity

Adults with special needs and their advocates (often caregivers) have strived for and achieved success in ensuring full participation in all aspects of life, including education, housing, employment, and community living. Individuals and groups have worked hard to increase understanding among people without disabilities about people with special needs.

Independent Living

In recent years, opportunities have increased and expanded for adults with special needs to choose preferred ways of living within the community. For instance, more housing options are available where individuals may choose to live alone or with others, in supported living arrangements (living with someone without disabilities), or in apartments.

Community Participation

Adults with special needs desire to have friendships and a sense of belonging and contributing to their communities like everyone else. They can join recreational groups, volunteer, and continue to learn and grow.

Economic Self-Sufficiency

Gaining the education and training one needs to have a job and become part of the workforce is expected of most adults. Employment fosters independence and allows feelings of connection to others while contributing to financial security. Gaining economic self-sufficiency may be possible by making full use of available resources and services.

DISCLAIMER

Resources cited and the appearance of hyperlinks do not constitute endorsement by the Department of Defense of the website or the information, products, or services contained therein. Other than for authorized activities such as Morale, Welfare, and Recreation sites, the Department of Defense does not exercise any editorial control over the information found at these locations. Such links are provided consistent with the stated purpose of this DoD-sponsored *Guide for Adults with Special Needs*.



Notes

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Introduction

Introduction to Module 2

Military life is unique, and filled with opportunities, benefits, and support systems for both service members and their families. Military life also comes with unique challenges. While being a military family member may not always be easy, there are programs and services available to help. Exploring the programs and resources available can help improve the quality of life for military family members, improve their overall well-being, and help support the service members as they carry out their duties.

Family Centers

The Family Centers are part of the installation family support system, which is the network of agencies, programs, services, partnerships, and individuals that supports personal and family life readiness, mobilization and deployment readiness, and mobility and economic readiness. This should be one of the first stops upon arriving at an installation; its programs and services are an important resource to service members and their families. Each Service has a specific name for its Family Center:



- Army: Army Community Service (ACS)
- Marine Corps: Marine Corps Community Services (MCCS)
- Navy: Fleet and Family Support Center (FFSC)
- Air Force: Airman and Family Readiness Center (A&FRC)
- Joint Bases: Warfighter and Family Readiness Center (WFRC)

Services may vary according to the installation's size and mission. Services offered may include:

- information and referral services
- spouse education and support programs
- exceptional family member support
- relocation services
- deployment support

- personal financial management
- family advocacy program
- family life education and workshops
- employment workshops
- individual and family non-medical counseling
- volunteer coordination

Exceptional Family Member Program

The Exceptional Family Member Program (EFMP) offers information about local organizations, support groups, referrals, resource assistance, and non-clinical case management services for families with special needs. For more information about the EFMP, refer to Module 9, [Moving Ahead](#). To find the nearest installation EFMP, visit the MilitaryINSTALLATIONS website (www.militaryinstallations.dod.mil).

Relocation Assistance Program

The installation Relocation Assistance Program (RAP) is the primary resource for all general relocation information. The program provides a wealth of moving and planning information designed to reduce the stress of frequent relocations. RAP services are structured to make the relocation process as smooth as possible. Additional resources and tools that can be customized are available at the Plan My Move website (<http://planmymove.militaryonesource.mil>).

The RAP provides:

- information on destination areas; preparation including details on moving costs, housing options, and home-finding assistance; child care; services for family members with special needs; spouse employment opportunities; schools; and cultural adaptation
- counseling about relocation-related challenges such as home buying, selling, renting, property management issues, and shipment/storage of household goods
- sponsorship training services, including connecting unit sponsors and family members, youth through youth sponsorship programs, and facilitating transitions to new communities



When you receive orders to a new duty station, you can request and be assigned a sponsor before you move. Request a sponsoring family with similar special needs from the installation RAP at your new duty station.

Deployment Support Program

The Deployment Support Program provides assistance throughout the deployment cycle. The installation Family Center has information on family readiness groups, non-medical counseling programs, and other deployment-related resources on the installation. Command-sponsored Family Readiness Officers (FRO), Family Readiness Groups (FRG), or Family Support Groups (FSG) provide activities and support to improve the flow of information, and practical tools for adjusting to deployments and separations.

Some branches of Service provide other non-medical counseling or support resources such as:

- non-medical counseling programs, to help increase coping skills and reduce the emotional stress of extended separations and worries regarding the safety of a deployed service member
- programs such as Family Team Building, to provide tools to improve family members' independence within the military culture through military acculturation classes, mentoring and leadership workshops, life-skills training, readiness and deployment support, and volunteer opportunities
- chaplains, to provide spiritual and pastoral support and non-medical counseling as well as personal, family, and marriage-enrichment programs

Personal Financial Management Program

To assist service members and their families in planning and controlling their financial future, the Department of Defense provides financial information, training, and counseling through the Personal Financial Management Program (PFMP), and additional information is available at Military OneSource (www.militaryonesource.mil/pfm). The PFMP is offered by each of the Services and is designed to assist members of the military in learning how to manage their finances and successfully plan their financial future. The PFMP provides classes, one-on-one counseling sessions, and additional information designed to educate service members and their families about consumer rights and to help them achieve financial stability.

Wesley pointed out that it can be a lonely road without the correct support. The family's EFMP case manager helped coordinate locally available services and connected him with TRICARE to get a home health aide, enabling Wesley to return to work.

Family Advocacy Program

The military community is not immune to personal or family issues. These concerns can range from minor stressors related to the unique demands of military

life to major difficulties that may place a family at risk for domestic abuse or child abuse and neglect. Services and supports are available to assist with these issues. The Family Advocacy Program (FAP) sponsors activities and services including public awareness briefings, individual and couples counseling, crisis intervention, victim advocacy, support groups, and stress management and other well-being workshops. FAP services may be found at military treatment facilities (MTFs) or installation Family Centers. Additional information can be found at Military OneSource (www.militaryonesource.mil/abuse).

Other Support Services

No matter what type of change, event, or issue that presents itself, assistance can be found through various military family programs. All Service branches offer family support on the installation. While programs vary by installation, most offer the following standard programs:

- Prevention education and counseling services – All branches of Service offer prevention education and non-medical counseling support programs, such as Military Family Life Consultants (MFLC). Licensed mental health providers offer non-medical counseling to military members and their families on topics including anger management, stress management, parenting, communication, family relationships, and deployment concerns.
- Non-medical counseling support through chaplains – Military chaplains provide counseling support to service members and their families, including individual, marital, and family counseling.
- Medical counseling services – Counseling is available at MTFs on military installations throughout the world. Services are provided by mental health professionals.

Relief Societies

Military communities pride themselves on taking care of their own. Relief societies exist to help families with unexpected problems or financial emergencies. Relief societies provide assistance for the following needs:

- emergency transportation
- funeral expenses
- disaster relief assistance
- child care expenses
- essential vehicle repairs
- unforeseen family emergencies
- food, rent, and utilities
- medical/dental bills (patient's share)

Each military Service is supported by a private nonprofit charitable organization that provides emergency financial assistance to active and retired service members and their families:

- Army Emergency Relief Society - (866) 878-6378, www.aerhq.org
- Navy-Marine Corps Relief Society - (703) 696-4904, www.nmcrs.org
- Air Force Aid Society - (800) 769-8951, www.afas.org

Service-Sponsored Websites

Each Service sponsors a website that provides information on military family quality of life programs. These websites also provide news articles, information related to the military lifestyle, and online tutorials:

- Army OneSource - www.myarmyonesource.com
- Marine Corps Community Services - www.usmc-mccs.org
- Fleet and Family Support Program - www.cnic.navy.mil
- Air Force Personnel Center - www.afpc.af.mil

Additional Military Resources

Military OneSource's EFMP Section

Military OneSource's EFMP section is the Department of Defense's (DoD's) official website to help service members and their family members who have special needs. This site is packed with information on benefits, allowances, and eligibility, and on military and civilian resources. Visit the EFMP section on Military OneSource (www.militaryonesource.mil/efmp) to find resources and support for:

- child care
- counseling
- deployment
- education for family members
- legal assistance
- moving and relocation
- new parent support



Need to talk?

Military OneSource is available twenty-four hours a day.

From the United States:
(800) 342-9647

International Toll-Free:
(800) 342-9647

International Collect:
(484) 530-5908

(Additional collect call information by country can be found at

www.militaryonesource.mil.)

TTY/TTD: (866) 607-6794

- personal financial management
- spouse employment
- transition assistance

Military OneSource provides information, referrals, and assistance to the military community. Accessed by telephone or the Internet, Military OneSource provides special needs consultations, research, resources, and materials intended to enhance current military services available to families with special needs.

A Special Needs consultant is available through Military OneSource for consultations on any number of issues related to individuals with disabilities or special needs. Specialty services can be accessed through the main telephone number for Military OneSource. All services are free of charge. For more information, visit Military OneSource (www.militaryonesource.mil/efmp).

Plan My Move

Plan My Move is a set of online organizational tools designed to make frequent moves easier and less disruptive for service members and families. Available tools include a customizable calendar, to-do lists, departure and arrival checklists, installation overviews, and installation-specific information on a number of topics, such as education, transportation, child care, and employment. To use this tool, visit the Plan My Move website (<http://planmymove.militaryonesource.mil>).

MilitaryINSTALLATIONS

MilitaryINSTALLATIONS is the DoD's official source for installation and state resources available to service members and their families. For articles, photos, major unit listings, and contacts for programs and services worldwide, visit MilitaryINSTALLATIONS (www.militaryinstallations.dod.mil).

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Notes



Notes

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Introduction

Introduction to Module 3

TRICARE is the worldwide health care program available to eligible beneficiaries of the seven uniformed services and certain National Guard and Reserve members (“beneficiary” refers to individuals who are entitled to benefits based on law). TRICARE is a major component of America’s Military Health System (MHS). The MHS brings together the health care resources of the uniformed services and supplements them with civilian health care professionals, institutions, pharmacies, and suppliers.



Enrollment in the Defense Eligibility Enrollment Reporting System (DEERS) is required

to access military family member benefits, including TRICARE. A service member’s military benefits can continue for an adult child over the age of twenty-one if the adult child is unmarried and has severe disabilities. The disability must have been due to a condition that existed prior to the individual’s twenty-first birthday, or twenty-third birthday for full-time students. To continue benefits under the Incapacitated Child Over Twenty-One program, the service member can contact the Installation DEERS Center for information and required documentation.

When seeking services under TRICARE, families must use TRICARE-authorized, civilian health care providers that include:

- network providers who have contractual agreements with TRICARE’s regional contractors (required use for Prime enrollees)
- participating providers, who are not part of the TRICARE network, but agree to accept the TRICARE allowable charge as payment in full
- non-participating providers who do not accept the TRICARE allowable charge as payment in full. **Note:** Beneficiaries are responsible for paying all charges up to fifteen percent more than the TRICARE allowable charge; they may also have to file their own claims

Go to the TRICARE website (www.tricare.mil) and choose the "Use the Plan Finder" to get more information about TRICARE options.

TRICARE is organized into four geographic regions: North, South, West, and Overseas. The TRICARE website (www.tricare.mil) offers links to the TRICARE regional websites and more information about TRICARE programs and benefits.

For more than thirty years, Marilyn and Pete have been caregivers for their son, who is unable to live independently due to a rare genetic condition. Keeping track of his records through multiple relocations was critical to successfully enrolling in services at new locations, managing TRICARE paperwork, and obtaining the identification and enrollment cards necessary for military dependents. *The Special Care Organizational Record for Adults* can be a helpful tool to keep track of family medical information and can be downloaded from www.militaryonesource.mil/efmp/special-care-org-records or ordered from Military OneSource.

TRICARE® Options for Active Duty Family Members

To meet the needs of active duty families, TRICARE offers several health care options available and differentiated by where the individual lives (e.g., overseas or near a military installation), relationship to the military (active, retired, survivors, former spouses, or National Guard or Reserve), and age (young adult or Medicare eligible). The sponsor's Service is responsible for determining TRICARE eligibility, not TRICARE.

TRICARE® Prime

TRICARE Prime is TRICARE's managed care option, similar to a civilian health maintenance organization. Active duty family members may choose to enroll in Prime; service members are required to enroll in TRICARE Prime or Prime Remote.

Prime enrollees receive their health care from a local military treatment facility (MTF) or civilian network provider. Enrollees must follow some well-defined rules and procedures, such as seeking routine care and getting referrals for specialty care from their Primary Care Manager (PCM), and obtaining an authorization from the regional contractor before seeking specialty care from a civilian provider. Failure to follow these steps may result in more costly point of service (POS) charges.

Prime coverage is available overseas through the TRICARE Overseas Program (TOP) Prime option. **Note:** Family members must be command-sponsored to enroll in TOP Prime. The overseas regional contractor must authorize all civilian specialty care.

In all MTFs, active duty service members have first priority for care, followed by active duty family members enrolled in Prime.

TRICARE® Prime Remote

Family members who live with their active duty sponsor and are either at least fifty miles or a one-hour drive from the closest MTF may enroll in TRICARE Prime Remote. Enrollment is required and enrollees must select a local civilian network PCM if there is one available in the local area. If one is not available, family members may use any TRICARE-authorized provider for their primary care needs. Contact the TRICARE regional contractor for help locating a provider.

Prime Remote coverage is available overseas through the TOP Prime Remote option. Family members must be command-sponsored to enroll. The overseas regional contractor must authorize all civilian specialty care.

Note: The TRICARE Young Adult (TYA) program is a premium-based health care plan available for purchase for qualified family members. TYA offers TRICARE Prime and TRICARE Standard coverage worldwide for unmarried family members who are at least twenty-one (or age twenty-three if enrolled in a full-time course of study at an approved institution of higher learning and if the sponsor provides at least fifty percent of the financial support) but have not yet reached age twenty-six.

TRICARE® Standard

TRICARE Standard is a fee-for-service option allowing eligible family members to see any TRICARE-authorized provider (e.g., doctor, nurse practitioner, lab, or clinic) without a referral. Please note that there are some services that require prior authorization; beneficiaries should check with their regional contractor's website or contact them for information about this requirement as it varies from region to region. Eligible family members, whose records are up to date in the DEERS, are covered under TRICARE Standard until they enroll in TRICARE Prime or Prime Remote. Standard offers greater flexibility and choice of providers. Beneficiaries must pay an annual deductible and ongoing cost shares for TRICARE-covered services. Standard beneficiaries may have to file their own claims.

TRICARE Standard is not available for active duty service members, but in some instances may be the only option for family members (e.g., when the family member does not live with the sponsor as required for Prime Remote, or when the family member is overseas but not command-sponsored).



Certain service members and their families may qualify for the Transitional Assistance Management Program (TAMP), which provides 180 days of transitional health care benefits beginning on the day after loss of eligibility for military health care. Visit TRICARE (www.tricare.mil) for more information on transitional health care benefits.

When enrolling in TRICARE Prime or TRICARE Prime Remote, it is important to note that enrollment forms for TRICARE Prime and TRICARE Prime Remote must be received by the regional/overseas contractor by the twentieth of the month for coverage to start the first day of the next month. This rule applies to family members.

The TRICARE catastrophic cap limits the amount of out-of-pocket expenses a family pays for TRICARE-covered services, including annual deductibles, Prime enrollment fees, pharmacy co-pays, and other TRICARE-allowable cost shares.

TRICARE® Extra

TRICARE Extra is a preferred-provider option allowing Standard beneficiaries to seek care from network providers with lower out-of-pocket costs (the beneficiary cost share is five percent less than under Standard).

With TRICARE Extra, there are no claims to file, but the choice of providers is limited to those in the network. TRICARE Extra is not available to active duty members and is not available overseas. For a comparison of benefit options, visit the TRICARE website and search "Benefit At-a-Glance."

TRICARE® after Retirement

TRICARE coverage options change when the military sponsor retires from active duty. For additional information, visit the TRICARE website and search "retirement." For a comparison of TRICARE benefit options, search "Benefit At-a-Glance."

Supplemental Health Insurance for Retirees

Supplemental health insurance is designed to cover the gaps in regular health insurance such as those due to deductibles or co-payments. Supplemental health insurance may be provided by another employer. If another health insurance policy is in place, TRICARE acts as the supplemental insurance for the employer-sponsored policy. For more information, visit the TRICARE website and search "supplemental insurance."

Pharmacy Benefit

The TRICARE Pharmacy Program (visit the TRICARE website and search "Pharmacy Program") offers multiple options for filling prescriptions. The least costly option is to fill prescriptions at an MTF. Three other options are:

- pharmacy home delivery
- TRICARE retail network pharmacies
- non-network pharmacies



TRICARE Online is the Department of Defense's (DoD) portal for beneficiaries receiving care within military treatment facilities. The portal provides secure, interactive access to a host of services, tools, and resources. Primary care appointments can be made, access to medical libraries is available, and links to information related to health and wellness, facilities, and providers are found by visiting the TRICARE website (www.tricare.mil).

TRICARE® Benefits for Families with Special Needs

To help eligible uniformed services families facing the extra challenges that come with managing special needs, TRICARE offers additional benefits.



Case Management

Case management is a system for organizing and integrating the many services that are often required to manage complex physical or emotional illnesses. It is designed to improve the quality of care, control costs, and support patients throughout catastrophic medical situations by providing a bridge between acute care and long-term care services. TRICARE offers case management to beneficiaries who have significant chronic or high-risk health issues. Beneficiaries with catastrophic or terminal illnesses may also qualify for case management. Case management services can be obtained by a referral from the primary care provider or through the Regional Contractor.

Mental Health Care

Unless the beneficiary has a serious mental illness that qualifies for care under Extended Care Health Option (ECHO), mental health care benefits can be confusing. Call the Regional Contractor for assistance in finding a mental health provider. The TRICARE website offers additional information regarding covered conditions and treatments. Visit the TRICARE website and search "conditions" and "treatments."

Hospice Care

Hospice care is designed to comfort terminally ill individuals and their families once it is determined that the individual is not expected to live more than six months. The hospice care goal is to provide dignity and comfort to the terminally ill. The vast majority of hospice care is provided at home or in nursing homes. TRICARE covers most hospice care costs, and it does not have limits on custodial care or personal comfort items under hospice rules. Beneficiaries must choose to be covered under the hospice benefit versus basic TRICARE benefits.

Extended Care Health Option (ECHO)

TRICARE ECHO supplements basic TRICARE coverage. This program provides financial assistance for certain services and supplies to qualified active duty family members (including eligible family members of activated National Guard or Reserve). The TRICARE website offers detailed ECHO information including enrollment details.

If TRICARE coverage is lost because of military separation, divorce, or because a dependent child reaches the age of twenty-one, a Certificate of Creditable Coverage will be issued. This is proof that previous health care coverage existed and limits the amount of time a new health care plan can exclude participation because of pre-existing conditions.

Who is Eligible for ECHO?

The ECHO is available to the following beneficiaries with a qualifying condition:

- active duty family members, including family members of activated members of the National Guard or Reserve on federally funded orders for more than thirty consecutive days
- family members eligible for continued TRICARE coverage through the Transitional Assistance Management Program (TAMP)
- children or spouses of former service members who were victims of physical or emotional abuse
- family members of deceased active duty sponsors during transitional survivor status

Note: Enrollment in the Exceptional Family Member Program (EFMP) is required to be eligible for ECHO benefits.

Qualifying Conditions

The following conditions qualify family members for TRICARE's ECHO:

- moderate or severe intellectual disability
- serious physical disability
- extraordinary physical or psychological condition causing the beneficiary to be homebound
- multiple disabilities may qualify if there are two or more disabilities affecting different body systems

If the family or family member's provider believes a qualifying condition exists, he or she should call the regional contractor to determine if the family member qualifies for coverage. If overseas, the family should contact the nearest MTF or TRICARE Area Office (TAO).

Note: Adult children may remain eligible for ECHO benefits beyond the usual TRICARE eligibility age limit as long as the sponsor remains on active duty; the beneficiary is incapable of self-support because of mental or physical incapacity that occurs before reaching the age limit of twenty-one, or twenty-three if a full-time student; and the sponsor is responsible for more than one-half of the adult child's support. Ongoing TRICARE eligibility is determined by the sponsor's Service. The regional contractor determines ECHO eligibility. Prior authorization must be obtained from the regional contractor or overseas TAO before the adult child receives ECHO services.

If the sponsor is reassigned, family members must get new ECHO benefit authorizations before receiving services at the new location. The regional contractor, local MTF, overseas TAO, or ECHO case manager should be contacted before a move to ensure a smooth transition.

ECHO Benefits

The ECHO program provides benefits not available through the basic TRICARE program, including:

- medical and rehabilitative services
- training to use assistive technology devices
- special education
- institutional care when a residential environment is required
- transportation under certain limited circumstances (includes the costs of a medical attendant when needed to safely transport the beneficiary)
- assistive services (e.g., those from a qualified interpreter or translator)
- durable equipment, including its adaptation and maintenance
- in-home respite care services (up to sixteen hours in the month if another ECHO benefit is received)

ECHO Costs

Active duty sponsors pay an ECHO cost share that is based on their grade and is separate from other TRICARE program cost shares. The military member pays one cost share per month an ECHO benefit is received by the family member(s), regardless of the number of family members receiving an ECHO benefit that month. For more information, visit the TRICARE website and search "ECHO costs."

Kyla used knowledge gained through EFMP to act as her own health care manager, coordinating with the doctors, the durable medical equipment (DME) provider, and TRICARE to ensure the approval process worked smoothly to receive the necessary DME, such as the wheelchair lift for their vehicle.

ECHO Home Health Care

ECHO Home Health Care (EHHC) provides medically necessary skilled services to registered ECHO beneficiaries who are homebound and generally require more than twenty-eight to thirty-five hours per week of home health services or respite care. In general, family members are considered homebound if they cannot leave home regularly for therapeutic, psychosocial, or medical treatment, or to attend an accredited, certified adult daycare program. The family member's PCM or attending physician determines eligibility for this home health care and will develop a care plan reflecting the home health care services the family member needs. This plan is reviewed by the physician, case manager, regional contractor, and/or TAO staff every ninety days or when there is a change in the family member's condition. The EHHC benefit is only available in the United States, Puerto Rico, the United States Virgin Islands, and Guam. Families should contact their ECHO case manager for more information.

TRICARE provides eight outpatient mental health visits each fiscal year without a Primary Care Manager referral. Family members may self-refer.

The sixteen-hour respite benefit available under ECHO cannot be used at the same time as the forty hours a week available under EHHHC.

EHHHC Benefits

The following services may be covered when provided by a TRICARE-authorized home health agency in the beneficiary's home:

- skilled nursing care by a registered nurse, or by a licensed or vocational nurse under direct supervision of a registered nurse
- services provided by a home health aide under direct supervision of a registered nurse
- physical therapy, occupational therapy, and speech-language pathology services
- medical social services under the direction of a physician
- teaching and training activities
- medical supplies

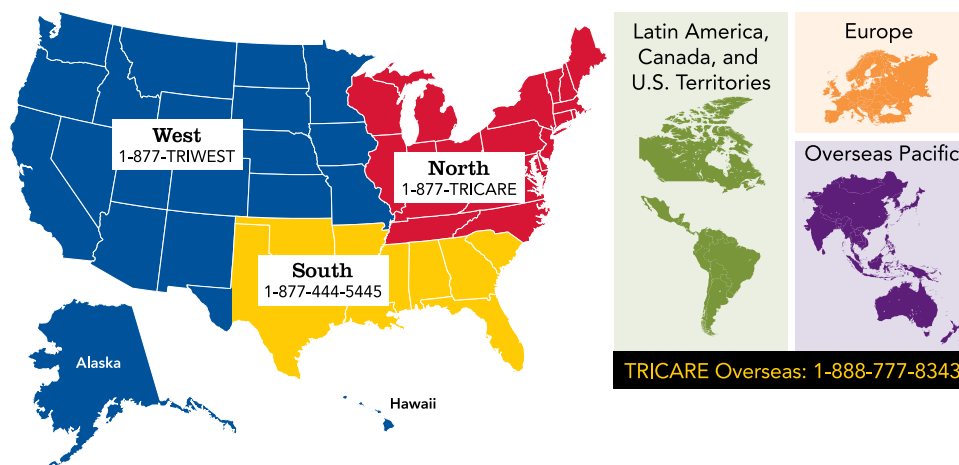
EHHHC Respite Care

EHHHC respite care is designed to provide temporary relief or rest for the primary caregiver of a homebound beneficiary who requires frequent care. Beneficiaries eligible for EHHHC respite care may receive eight hours of respite care, five days per calendar week. This benefit is different from the sixteen hours of respite care available through ECHO. The EHHHC respite care and ECHO respite care cannot be used during the same month. Respite care cannot be used for babysitting/child care services, sibling care, or when the primary caregiver is deployed, seeking employment, or pursuing education. Unused respite care hours are not cumulative.

TRICARE® Help and Information

Program information regarding TRICARE eligibility, Prime/Prime Remote enrollment, benefit and cost information, claims filing, and more can be found by visiting the TRICARE website (www.tricare.mil).

TRICARE® Services Map



Questions related to plan options, enrollment, referrals and authorizations, claims, collection, and TRICARE benefits can be answered by the regional contractor office. Call the regional contractor with any questions. They have the most current information regarding benefits specific to a region. When contacting TRICARE, have information on hand, such as referrals, authorizations, medical/dental bills, denial letters, and debt collection notices, to assist staff in determining how best to proceed. For contact information, visit the TRICARE website and search "region."

TRICARE® Service Centers

TRICARE Service Centers (TSC) are located in or around most MTFs and are staffed with customer service representatives to provide help on a walk-in basis.

Beneficiary Counseling and Assistance Coordinators/Health Benefits Advisors

Regional offices' and most MTFs' beneficiary counseling and assistance coordinators (BCAC) can provide information on accessing care within the MTF, as well as refer beneficiaries to the right office for more information on benefit options, enrollment questions, claims, referrals, authorizations, and appointments. The BCAC can facilitate communication between families, the MTF, and the TRICARE contractor.

Debt Collection Assistance

Regional contractor staff and Debt Collection and Assistance Officers (DCAO) at MTFs help beneficiaries with TRICARE debt collection issues. Beneficiaries who either receive notices from collection agencies about medical bills or who are disputing medical bills should contact the regional contractor or closest DCAO for guidance. When seeking assistance, bring all documentation related to the claim and the collection action or billing dispute. Staff can help with claims and the debt collection process but cannot provide legal advice or fix a credit rating. For assistance with a collection action, contact the regional contractor or find the nearest DCAO by visiting the TRICARE website and searching "DCAO."

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Notes

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Introduction

Introduction to Module 4

Self-determination is key to achieving equal opportunity in daily life by knowing and understanding laws, rights, and methods of advocacy impacting access to services. Self-determination (See Life Domains Addendum; A:7) is the principle that every adult has the right to make life decisions. Understanding strengths and limitations and believing in oneself is essential to exerting control and direction in life and achieving goals.

Establishing a network of friends and others who can provide support and guidance is also helpful to gain and maintain as much independence as possible.



Laws and Rights

Over the past several decades, civilian and military advocates have worked to bring about legal, medical, and social changes to address the needs of individuals with special needs. These pioneers have paved the way for improved services and resources in many areas and have encouraged the passage of three important laws: the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA), and the Rehabilitation Act (Sections 504 and 508). These laws are designed to protect the rights of individuals with special needs and allow them to enjoy equal opportunities, independent living, community participation, and economic self-sufficiency.

Individuals with Disabilities Education Act

The 2004 IDEA (<http://idea.ed.gov>) governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. The IDEA ensures that individuals between the ages of three and twenty-two who have disabilities may receive a free and appropriate public education, and assistance with their transition from school into adulthood.

Equal Opportunity

4

Americans with Disabilities Act

The 1990 ADA (www.ada.gov) is a landmark law that was amended in 2008 as the Americans with Disabilities Act Amendments Act (ADAAA). The law provides civil rights protections to individuals with disabilities. It guarantees equal opportunity in employment, state and local government, public accommodations, telecommunications, and transportation. The ADA protects the rights of those with a disability and those who provide care for someone who has a disability.

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 (<http://ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>) prohibits discrimination on the basis of disability by any public or private program that receives federal funding. It is similar to ADA, but covers only federally assisted programs, and thus is narrower in scope than ADA. Requirements common to these regulations include reasonable accommodation for employees with disabilities, program accessibility, effective communication with people who have hearing or vision disabilities, and accessible new construction and alterations.

Section 508 of the Rehabilitation Act of 1973

Section 508 of the Rehabilitation Act of 1973 (www.section508.gov) requires federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public.

Some common questions and answers regarding the major laws that protect the rights of individuals with a special need are provided below:

IDEA Question: What are the educational rights under the Individuals with Disabilities Education Act (IDEA) of 2004 for young adults with special needs as they transition into adulthood?

IDEA Answer: The IDEA ensures that children and youth with disabilities are provided a free, appropriate public education. School systems differ regarding how long youth and young adults may receive special education services.¹ The IDEA requires transition planning to be addressed by the Individualized Education Program (IEP) team beginning at the age of sixteen. While in high school, parents and teachers provide much of the support needed for success. Transition services are designed to assist the student as they leave school for adult living. The process of transition begins at least one year before a student reaches the age of majority under state law. During this time, the student's IEP must include a statement informing them of the rights that will transfer upon reaching the age of majority.

¹ States may define 'age twenty-one' as the date the student has a twenty-first birthday, or as the end of the twenty-first year, or the twenty-second birthday.

Note: During the transition process, parents should discuss the “age of majority” with young adults to prepare them for their new rights and responsibilities. It is also a good time to have a discussion about the role parents and/or caregivers will have in their lives.

In recent years, many states have developed educational and employment programming for students between the ages of eighteen and twenty-two with disabilities. These programs allow students to continue to receive special education and related services in the community. Some students may attend community or four-year colleges in a nontraditional program, while others may gain valuable work experience in the community. A student with significant disabilities should have a transition plan describing any post-secondary goals. The transition plan will assist the preparation for post-secondary life.

Note: The transition of young adults from high school to post-secondary education or an independent life presents many new challenges and opportunities. Students with an IEP have no entitlement or guarantee of receiving services when they leave high school. These young adults with disabilities must apply and be eligible to receive assistance. For example, adults must apply for vocational rehabilitation services to receive education, training, or support for employment. If they do not meet eligibility criteria, or if there is a waiting list, they will not be accepted for services.

ADA Question: How does the ADA help to support employment?

ADA Answer: The ADA prohibits discrimination in all employment practices, including job application procedures; hiring; firing; advancement; compensation; training; and other terms, conditions, and privileges of employment. It applies to recruitment, advertising, tenure, layoff, leave, fringe benefits, and all other employment-related activities.

Section 504 of the Rehabilitation Act of 1973 Question: How does the Rehabilitation Act of 1973, as amended, protect individual rights?

Section 504 of the Rehabilitation Act of 1973 Answer: Section 504 protects individuals with a special need with the right to not be discriminated against in recruitment, admission, or treatment in education and employment. Individuals with special needs may qualify for protection under Section 504 if they have a physical or mental impairment that substantially limits one or more major life activities, have a record of such impairment, or are regarded as having such impairment. Under Section 504, people with special needs have the right to request modifications, accommodations, or auxiliary aids that will enable them to benefit from certain programs.

For more information about the ADA, contact the Information Line at the U.S. Department of Justice: (800) 514-0301 (voice) (800) 514-0383 (TTY).

Section 504 is particularly important to students with documented special needs who are not covered under the IDEA, but still require additional assistance.

It also protects eligible adults with special needs who want to access services from any agency or program that receives federal money.

Section 504 of the Rehabilitation Act of 1973 Question: What are “major life activities” as defined by the Rehabilitation Act?

Section 504 of the Rehabilitation Act of 1973 Answer: Major life activities include functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. The Rehabilitation Act also provides vocational training, education, and employment services for adults with special needs who meet its eligibility criteria. To locate agencies that provide vocational rehabilitative services in a specific state, visit Military OneSource (www.militaryonesource.mil/efmp).

Section 504 of the Rehabilitation Act of 1973 Question: How is an individual protected from employment discrimination?

Section 504 of the Rehabilitation Act of 1973 Answer: Employment discrimination is prohibited against “otherwise qualified individuals with disabilities” who are applicants for employment and employees. An individual is considered to have a disability if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such impairment. Those discriminated against because they have a relationship with an individual with a special need are also protected.

The first part of the definition applies to individuals who have impairments that substantially limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working. An individual with epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, mental retardation, or a specific learning disability is covered, but an individual with a minor, nonchronic condition of short duration, such as a sprain, broken limb, or the flu, generally would not be covered.

The second part of the definition protects individuals with a record of a special need, and covers, for example, a person who has recovered from cancer or mental illness.

The third part of the definition protects individuals who are regarded as having a substantially limiting impairment, even if the impairment does not directly

impact their abilities. For example, this provision protects a qualified individual with a severe facial disfigurement from being denied employment because an employer feared the “negative reactions” of customers or coworkers.

Section 504 of the Rehabilitation Act of 1973 Question: Who is an “otherwise qualified individual with a disability”?

Section 504 of the Rehabilitation Act of 1973 Answer: An otherwise qualified individual with a disability is a person who meets the skill, experience, education, or other requirements of an employment position that is being held or sought and can perform the essential functions of the position with or without reasonable accommodation.

Section 504 of the Rehabilitation Act of 1973 and ADA Question: What is a “reasonable accommodation”?

Section 504 of the Rehabilitation Act of 1973 and ADA Answer: A reasonable accommodation is any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a special need to participate in the application process or to perform essential job functions. The accommodation must not present undue hardship on the employer (this is determined on a case-by-case basis). Research has shown that accommodations in schools or workplaces, such as allowing a student to answer test questions orally or rearranging furniture to allow ease of access, often cost less than \$100; these accommodations are paid for by the school or employer.

Understanding Systems

A key to working with health care, vocational rehabilitation, developmental disability services, and mental health services is to understand that they can be complicated systems to access. Each system offers different services, often with multiple providers. Each program will have separate and different eligibility requirements and rules for participation. Information about local systems that provide support can be found through the Department of Health and Human Services website (www.acf.hhs.gov/programs). Public programs are often limited due to a chronic shortage of funding. When seeking services, it is essential to be assertive and persistent when applying for, obtaining, and utilizing services.

In most states, youths at the age of eighteen are legally adults and can sign health care documents and have their own legal signature.

Being able to describe the special need and how it affects the ability to perform is important. For example, rather than telling a professor or employer that “I have a learning disability,” one could say “I have trouble keeping up with and understanding lectures or oral directions, but if someone can take notes for me—especially electronically—I can do well.”

The Mechanics of Effective Advocacy

Effective advocacy includes developing the skills to make appropriate decisions, problem solve, and set goals for the future. Advocacy includes skills such as:

- Communicating individual needs and desires in an understandable manner or in language that is clear and concise
- Speaking up for oneself or the adult with special needs
- Communicating individual strengths, needs, preferences, and goals
- Listening to the ideas of others
- Respecting oneself and others
- Understanding the laws and rights that protect individuals with disabilities
- Finding out where to get help
- Knowing how to ask for accommodations
- Finding and keeping in touch with advocacy organizations
- Knowing when and how to disclose personal information

Doctors originally recommended lifetime care in a specialized facility for Tony, when he was born with a severe genetic condition. Rather than following that advice, his parents, Marilyn and Pete, chose to keep Tony with the family. Marilyn admits, “Standing up for what you believe is right for you and your family is hard, especially when dealing with doctors and an established system—however, perseverance pays off.”



Positive Advocacy Strategies

It is important to remember that advocacy often concerns gaining the same rights that others have or may take for granted. An essential first step in advocacy is to understand the special need; how to describe it; and how it may affect the ability to learn, behave, and perform. Other recommended strategies are provided in the following list.

Recommended Advocacy Strategies	
Seeking information and assistance from others	<ul style="list-style-type: none"> Who has the information that could be helpful? What are the available resources or support organizations?
Sharing problems or issues and seeking support from family or friends	<ul style="list-style-type: none"> Who is available to share information? Who will understand and provide support?
Relying on positive people	<ul style="list-style-type: none"> Are there friends and individuals in the community who can be encouraging and sympathetic? What organizations are available to help in the development of positive, supportive relationships?
Making short-term or daily goals	<ul style="list-style-type: none"> How can tasks be broken down into more manageable steps? What assistance can be found to help accomplish goals or tasks?
Mastering the vocabulary and terminology associated with the special need	<ul style="list-style-type: none"> Who has the information necessary to become familiar with terminology associated with the special need? What terminology do the service agencies or providers use?
Thinking positively	<ul style="list-style-type: none"> What are one's known strengths, skills, and abilities? How can daily life be improved? How can positive thinking skills be developed and practiced?
Accepting and dealing with feelings of frustration, disappointment, and anger	<ul style="list-style-type: none"> Are there more productive ways to deal with the emotions associated with the special need? What support is available in acknowledging and working through negative feelings?
Taking care of oneself	<ul style="list-style-type: none"> What steps are necessary to ensure sufficient rest, nutrition, and health? Are there programs available that can support good health?
Using a positive attitude when dealing with others	<ul style="list-style-type: none"> Who provides additional physical and emotional support? What ways can appreciation and understanding for their efforts be shown?

It is important always to be polite and friendly. Keep in mind that the response of “no” is not always final. If things are not working the way you would like, be persistent in asking for help or other solutions.

Obtaining Needed Services

When exploring or seeking services with agencies or government entities, bureaucracy can become a problem. While there is no easy solution, it is important to persist. The following strategies may be helpful:

- Be prepared. Find out as much as possible about the agency and its services and requirements before scheduling an appointment by researching via the public library or Internet.
- Inquire what other options or services are available and ask about the recommended next steps.
- Ask who else can help, if they can provide alternative resources, or make needed referrals.
- It may be necessary to call or revisit the agency/person to ask if the situation or funding has changed.
- Investigate similar services, resources, or agencies in another area.
- Always document each conversation, phone call, email, or other contacts.



The Health Insurance Portability and Accountability Act (HIPAA) and similar privacy laws mean that health care providers, employers, and educational institutions are not allowed to share information with caregivers without permission from the individual with special needs. Once caregivers are given written permission to access the information, they need to keep in mind they are not then responsible for making decisions. Their role is to provide assistance as an observer or a partner in the process.

Barriers

When navigating the various service systems, a number of barriers or systemic issues can make the process of determining eligibility or obtaining services lengthy and time consuming. These and other barriers, such as disagreements between policies (which prevent collaboration), communication breakdowns, and staff turnover can make obtaining services difficult. While there may be no easy way to deal with these concerns, it is worthwhile to keep trying.

“You may be overwhelmed, and it may be hard to accept at first that you now have special needs. Not everyone is proactive, and not everyone will do the research, but it is so important.”
— Kyla, adult with an acquired disability.

Each state provides funding for vocational rehabilitation, developmental disability, and mental health services for adults with special needs; however, funding can be limited. Not all requests can be met in a timely manner or at all. For this reason, it is important to research and apply for appropriate services as soon as possible, knowing that they may not be available immediately.

Potential Barriers to Services	Strategies to Overcome Barriers
Lengthy and challenging paperwork	Make duplicate copies of forms; seek assistance from other adults familiar with the process
Long waiting lists to receive services	Research available programs and services; submit application for eligibility determination as early as possible
Limited openings for services	Look for other community programs that may offer similar services; contact the state Protection and Advocacy System (www.acl.gov/programs/aidd/Programs/PA/Contacts.aspx) for additional assistance
Strict, inflexible, or confusing eligibility requirements	Seek assistance from advocates or advocacy organizations, such as the National Disabilities Rights Network (www.ndrn.org)
Information request redundancy	Keep organized and complete records; use the Special Care Organizational Record (www.militaryonesource.mil/efmp/special-care-org-records) to keep a readily available master file of information that is repeatedly requested
Lack of or restricted access to health and medical records	Obtain and sign HIPAA (www.hhs.gov/ocr/privacy) paperwork to allow access to records
Adult services agency personnel repeatedly delaying appointments	Document each phone call, electronic communication, and conversation; if personnel contacted is nonresponsive more than three times in a row, contact a supervisor; always document the name of the person providing the information, including title and direct phone number

When Services or Situations Are Not Ideal

At times, situations may not be ideal. Many systems have stringent cut-offs (meaning they have a limit to how many people they can serve at one time or within a certain time period) or requirements that vary. Sometimes individuals may have to accept services they consider inadequate, but are the only option available. Settling for only services that are affordable may become necessary. While there is no easy answer, it is essential to find and maintain a support network of family and friends, or possibly a helpful professional, to supplement any situations that may not meet full expectations.

Building Partnerships

Other positive strategies that support advocacy efforts involve building a network of families, friends, service providers, and caregivers. This face-to-face support can be supplemented by using virtual social networks through such places as special-need-specific websites, professional organizations, or military-related groups. Some common characteristics of helpful networks or partnerships can include those that are reliable, responsive to one's needs, flexible, and trustworthy.

Finding Resources and Support

Regardless of who has the special need, everyone involved with managing care can struggle with similar emotions and concerns. Communicating openly provides a number of positive outcomes and can ease shared fears, open topics for discussion, and provide an opportunity for friends and family to work together to ensure the needs of everyone involved are met.

While a friend or family member cannot legally make decisions for another adult without being appointed as the legal guardian, they can help communicate needs, research programs and services, assist in the decision-making process, and provide moral support. Efforts may also include support for the caregiver, such as giving the caregiver respite time away.

Support can also be found outside the circle of family members and friends. Each situation is unique—some families face financial, emotional, and logistical challenges that others do not. It is up to the individual to seek out resources to help meet personal, family, or caregiver needs. Support systems are available to provide nonjudgmental help with feelings and experiences. Service members and their families have many groups and agencies to turn to for help.

Support Groups

Local support groups can offer a place to share feelings and find solutions with others who understand the challenges of managing a special need. If it is difficult to get to a support group, some find it helpful to connect with others on web-based discussion boards. Many websites, networks, and online communities exist for various special needs.

Resource Centers and Networks

Resource centers or networks can be located through local, state, or federal organizations. Disability.gov (www.disability.gov/health) provides a search tool for finding special-need-related health information and organizations.

There are several national organizations that provide resources for caregivers, including web-based educational pamphlets, online support groups, and advocacy opportunities. These organizations often lead to local resources, including educational classes and professionals who can provide support. The following are examples of national caregiver organizations and/or websites:

- Family Caregiving Alliance (FCA) (www.caregiver.org/caregiver/jsp/home.jsp) – FCA supports and assists families and caregivers through education, advocacy, and services. The National Center on Caregiving (NCC), which is available on that website, is a source of information on caregiving and long-term care issues and works to advance policies and programs for caregivers throughout the United States.
- National Alliance for Caregiving (www.caregiving.org) – A coalition of organizations focused on family caregiving issues, the National Alliance for Caregiving conducts research and policy analysis and develops national programs to increase public awareness of family caregiving issues.
- National Family Caregivers Association (www.thefamilycaregiver.org) – A grassroots membership organization for family caregivers, the National Family Caregivers Association provides education, information and referral services, and advocacy.



For more information on community-based resources organized by state, visit Military OneSource's EFMP section.

Community-Based Services

Obtaining services for adults with special needs typically begins with applying for programs and services through the Social Security Administration, Vocational Rehabilitation Services, Mental Health or Intellectual Disability Services, adult education programs, and other state or local agencies. Eligibility for programs or services is based on the special need and how it impacts daily life.



Most communities offer a range of programs and services for adults with special needs. When working with community-based agencies, ask if the agency provides case managers or service coordinators who can assist in navigating the program, and who may be able to help locate other appropriate services. These professionals are knowledgeable of other services,

including eligibility requirements, offered programs, referrals, applications, and availability.

Department of Social Services

Each state has a Department of Social Services that offers programs and services to help adults with special needs become more self-sufficient. Most of these departments offer information, assistance, and referrals to:

- home-based services (companion, chore, and homemaker services)
- adult foster care
- adult day care
- case management
- nutrition education
- assessments for adults entering or residing in assisted-living facilities
- screenings for adults entering nursing facilities or who need Medicaid-funded Home- and Community-Based Waivers
- state Medicaid programs
- abuse and neglect prevention
- public benefits such as energy assistance, food assistance, or other general assistance programs

Department of Vocational Rehabilitation Services

The Department of Vocational Rehabilitation Services (VR) is a state-operated program offering a variety of programs and services to find and maintain employment. Each state, territory, and the District of Columbia has a VR agency. VR services include:

- assessment, including vocational or career assessment, counseling, and referral
- on-the-job training
- supported employment services
- job placement services

Department of Mental Health, Substance Abuse, or Behavioral Services

Each state offers community-based programming for individuals with mental health, substance abuse, or other behavioral diagnoses. While services vary greatly from location to location, some communities offer:

- evaluation and vocational or career assessment
- vocational assistance or programming
- outpatient clinical services (counseling/therapy)
- individual service planning
- residential treatment
- medication education and management
- case management
- support and treatment groups
- day programs
- clubhouses
- psychiatric treatment facilities

Center for Independent Living

State Centers for Independent Living (www.ilru.org—search "state directory") offer programs within a local community run by and for people with special needs. The goal is to develop leadership, empowerment, independence, and productivity. Centers provide an array of independent living services including:

- information and referral
- independent living skills training
- peer counseling
- individual and systems advocacy

The Arc

The Arc (www.thearc.org) is a national community-based program that provides support and services for people with intellectual and developmental disabilities. It can offer information on programs available through its local chapters, such as:

- information and referral
- individual advocacy to address education, employment, health care, and other concerns
- self-advocacy initiatives
- residential support
- family support
- employment programs
- leisure and recreational programs

Easter Seals

Easter Seals (www.easterseals.com) provides services, education, outreach, and advocacy for people living with special needs, enabling each person to live, learn, work, and have fun in the community. Some of the services offered include:

- information and referral
- center-based adult day care
- in-home care
- medical support, medication administration, and management
- respite care
- job training and employment
- assistive technology resources
- social support
- camping and recreation

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Notes



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Introduction

Introduction to Module 5

Independence is important to all individuals whether or not they have a disability. There are many services, programs, and tools available to facilitate independent living. Resources to support and manage daily life in areas such as living options, home modifications, housing assistance, transportation, and personal assistance are available through various agencies and organizations.

Note: Independence is defining who decides how a task or responsibility will be carried out, and not just a matter of whether someone does something for him- or herself. To foster independence, caregivers function in ways that are collaborative. Being independent is taking responsibility for mistakes, learning together, and accepting each other's abilities and limitations. It is also maintaining positive relationships with mutual respect and open communication.

Independent Living Options

Options for living arrangements vary greatly depending on individual abilities and preferences. Some live at home with their family, alone in their own home or apartment, in a community living arrangement, or in a more structured residential environment. When

considering a long-term living arrangement, it is critical to plan for emergencies, including when the primary support person is not able to provide for lifelong care. Planning ([See Module 8, Legal and Financial Issues; Why Planning is Important](#)) for caregiving options prior to a crisis can alleviate some of the inevitable stress that occurs when the balance of care shifts within a family.

Housing Assistance Programs

Individuals with disabilities may be eligible for housing and household assistance through several federal/state programs if they plan on living away from their sponsor or family. There are several types of housing and household assistance that help people with special needs afford appropriate housing in the private sector. Many options are available and explained by state and territory on the Disability.gov (www.disability.gov/housing) website (select "National Resources" or an individual state, and type "special needs" in the search box).



Independent Living

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For other types of housing assistance programs, visit www.disability.gov to find state, city, or disability-specific websites.

Section 8 of the Housing Act (portal.hud.gov—search Section 8) assists low-income and disabled individuals in securing housing using two types of portable subsidies. The first subsidy helps qualified individuals pay their rent. The rental assistance is paid directly to the landlord, which in some cases can be a relative. The second subsidy helps qualified first-time home buyers pay their mortgage. This program has financial requirements, though some vouchers may be set aside for those with disabilities. If considering this option, be aware that this program tends to have long wait lists and may not be available in some areas. For additional information on Section 8 housing, visit the Department of Housing and Urban Development (HUD) website.

Low Income Home Energy Assistance Program

The Low Income Home Energy Assistance Program (LIHEAP) is a federally funded, state-administered program that can assist those considered low-income or those who receive assistance under certain other federal programs. LIHEAP helps with bill payments, energy crises, weatherization, and energy-related home repairs. When considering this program, be aware that the eligibility and program application criteria differ from state to state. Information on LIHEAP can be found through the Department of Health and Human Services (HHS) website (www.acf.hhs.gov/programs/ocs/programs/liheap) or by calling the National Energy Assistance Referral (NEAR) project at (866) 674-6327.

Universal Services Fund

The Universal Service Fund (<http://transition.fcc.gov>—search "Universal Service Fund") is offered through the Federal Communications Commission (FCC). It can help individuals establish and maintain discounted telephone service. Eligibility for this program is contingent upon meeting certain

financial requirements or participation in certain public benefits programs. Additional information on the Universal Services Fund and other services that may be helpful for individuals with special needs can be obtained by contacting the local telephone service provider.



Home-Based Services

Home-based services allow individuals with disabilities to live in their own homes while receiving supportive services. These services help increase independence and relieve family members of some of the caregiving responsibilities. They can be arranged privately, through home health agencies, or other agencies serving those with disabilities.

Professional Caregivers

Professional caregivers are most commonly used to assist with the tasks of daily living. Individuals who have restricted mobility may require help with household duties or self-care, such as bathing or dressing. Professional caregivers are typically hired through a health care agency. If eligible, Medicare or Medicaid may be available to pay for these services and require agency-certified caregivers. Also, TRICARE or an insurance carrier may also cover some of these costs. For additional information, visit the Disability.gov website (www.disability.gov) and search caregiving.

Hiring a Professional Caregiver

Whether using an agency or employing a private caregiver, be sure the professional caregiver can meet personal needs. Interviewing the proposed caregiver ([See Health Care Addendum 4, A:4](#)) before they begin providing services is essential. Questions should be tailored to determine if the person can meet all of the physical, emotional, and/or cognitive needs of the individual. If the professional caregiver requires a license, be sure to check with the state to verify the status of the license.

As the professional caregiver becomes a part of the support system, it is important for all involved to keep the lines of communication open. If family members are involved with the professional caregiver, it is important to provide positive opportunities to share suggestions, offer praise, and provide constructive feedback if changes need to be made. If the professional caregiver works through an agency, it is important to communicate directly with the agency as well. Regular contact with the agency can be helpful in limiting unexpected or sudden changes in personnel.

Homemaker Services

Homemaker services provide a wide range of services. Having someone to complete difficult chores can reduce stress and allow additional time to participate in other activities. For individuals with limited energy or mobility, homemaker services may be a necessity. Hire someone to assist with daily living



If eligible, funding for a professional caregiver may be available through Medicaid, Medicare, or TRICARE.

The Telecommunications Act of 1996 (www.access-board.gov) requires manufacturers of telecommunications equipment and providers of telecommunications services to ensure that their equipment and services are accessible and usable by individuals with disabilities.

and household chores by contacting local agencies, advertising in the paper, posting an ad at the local college, or getting referrals from a family friend. Many local nonprofits or religious-based groups offer listings of volunteers.

Homemaker services most often assist with daily tasks such as:

- yard work or lawn maintenance
- house cleaning
- laundry
- shopping or running errands
- meal planning and cooking
- personal care
- pet walking and grooming
- child care

Companionship Services

When managing a special need, it may be difficult to develop personal relationships or to ask for assistance with the routine tasks of daily life. Companionship services make activities such as grocery shopping, preparing meals, making and getting to appointments, or attending recreational activities more enjoyable and easier to perform. These services often help those with special needs become part of the community and provide access to activities that they may not be able to manage on their own. Local nonprofit groups, religious or fraternal organizations, or disability-specific support organizations or groups can help individuals locate companionship services.



Nutrition Programs

Nutrition programs provide assistance with meal planning, grocery shopping, or meal preparation. Most communities offer programs that provide this level of service and can include:

- online grocery shopping and home delivery
- home delivery pre-prepared meals
- food delivery through Meals On Wheels programs

- grocery store meal-to-go services
- senior center or disability-related center meal programs
- community food banks or pantries
- nonprofit- or religious-based lunches or dinners

Home Modifications and Assistive Technology

Whether living on a military installation or in the community, it is important that the selected home meets the requirements of the individual with special needs. Ensure the home is accessible and can accommodate any needed extra space for maneuvering special equipment. Many installation housing offices and apartment complexes provide floor plans on their websites.

Universal Design

Homes built using universal design allow accessibility for every member of the house. Universal home design often utilizes minimal adaptive equipment with minimal additional cost. The goal of such a home is to make a friendly, warm environment that is usable by all without requiring excessive adaptive equipment. Many characteristics are subtle and may not be easily differentiated from a home that does not use universal design. The “Informed Consumer’s Guide to Accessible Housing” is available on Disability.gov (www.disability.gov) and offers a wide variety of information on universal design and accessible housing.

Determining Modifications

If the residence does not meet the individual’s special needs, modifications or adaptations to the residence may be considered. The Housing Office will be able to assist with questions regarding modifications of military housing. The Center for Independent Living (www.ilru.org—search home modifications) offers information regarding home modifications and can assist in locating a specialist trained in housing accessibility who can help:

- determine what changes need to be made
- evaluate requirements for equipment
- support an application for assistance programs

Kathy and Mike made modifications including a wheelchair lift, an elevator to the upstairs bedroom/bathroom area, and enlarging the master bedroom to allow Kathy easier wheelchair access.

The specialist can develop a list of necessary modifications, which will be useful when shopping for items, ordering equipment, working with a contractor, and applying for grants and HUD agency loans. In addition to general safety issues ([see the Safety and Accident Prevention Addendum; A:10](#)), consider the following when determining if modifications for accessibility are required:

- all necessary appliances, sinks, etc., are within reach
- accessible main entry
- covered porch
- doorway width of at least thirty-six inches
- paddle or lever-type door and faucet handles
- hallways and rooms that are maneuverable and large enough to accommodate equipment
- fully accessible bathroom in the individual's room
- handheld shower heads and lower faucet controls
- lowered countertops, cooking surfaces, cabinets, and open shelf space
- wall ovens
- drawer dishwasher
- intercom system
- emergency call abilities from the bed/bathroom
- easy-to-reach light switches and electrical plugs
- wood, tile, or linoleum flooring, or low-pile carpeting
- U-shaped drawer or cabinet pulls
- grab bars in the bath, shower, and toilet area, specifically placed for the person who will be living in the room, apartment, home, etc.

As Betty adjusts to limited mobility from a degenerative bone disease, modifications to the bathroom, including an elevated toilet seat with grab bars, a long-handled bath sponge, nonskid shower mats, and a shower chair help Betty take care of her own hygiene needs.

Funding for Modifications

Many home modifications cost very little. If additional financial assistance is needed for more extensive modifications, consider the following options:

- Talk to the physician to see if a prescription can be written to allow health care insurance to cover medically necessary equipment.
- Contact the local Center for Independent Living (www.virtualcil.net/cils), area Agency on Aging (www.n4a.org—search by local area), or other state/local disability services organizations for information or referrals to funding sources.
- Contact the Department of Social Services, which may be able to assist with funding through Medicare, Medicaid, and the Medicaid Home and Community-Based Services Waiver.
- Seek assistance through local clubs, private foundations, community service groups, churches, or sorority/fraternity service organizations.
- Ask the local vocational rehabilitation program for information on how it can assist through their independent living projects or by paying for assistive technology or providing on-site assessment for modifications that are in some way related to the individual's potential to be employed.
- Call the local Social Security office (www.socialsecurity.gov/pgm/medicare.htm) to see if any of the needed equipment might be covered under Medicare.
- Call the local Veterans Administration (<http://benefits.va.gov/homeloans>) to see if funding is available.
- Contact the local public housing authority, Office of Community Services, Supportive Services, or Section 8 Housing Authority to ask if they offer assistance for housing modifications for people with disabilities.
- Negotiate with the builder/seller of a home to have needed modifications specified in the lease, or purchase agreement.
- Ask other individuals or families with disabilities how they funded home modifications.

Assistive Technology

Assistive technology (AT) is a device or service that is off the shelf, modified, or specially created to reduce the effect an illness or disability has on a person's quality of life. The type of AT needed is determined by the individual's ability, the environment, and the activity to be performed. AT includes everyday items such as magnifying glasses, electric can openers, or easy-to-use door handles. For those who require mobility assistance, assistive technology includes ramps, nonskid pads, grab bars, canes, walkers, wheelchairs, or robotic devices. Higher technology devices such as computers or handheld devices can help those who need assistance with organization, scheduling, communication, transportation, or directions.

The Assistive Technology Act of 2004 provides funding to develop statewide information and training programs to provide assistive technology to individuals with disabilities to support participation in education, employment, and daily activities across a variety of learning and living environments.

Funding and Resources for Assistive Technology

AT devices may be expensive for adults with special needs to obtain. One of the TRICARE Extended Care Health Option (ECHO) benefits (www.tricare.mil—search "ECHO"), Durable Medical Equipment (DME), may cover some of the costs associated with AT devices.

Assistance on accessing AT services and equipment exchange programs can be found by contacting the local American Red Cross, Easter Seals, Parent Training and Information (PTI) Centers, and disability support organizations. Additional information can be found through the Rehabilitation Engineering and Assistive Technology Society of North America (www.resna.org).

Supported Living Arrangements

Supported living arrangements provide support services in a living environment designed to maintain the ability to function independently. Supported living arrangements vary greatly and can range from a small, home-like residence to a large, multi-floor facility. Professional staff members are available during specific times of the day and week, and can include professional nurses or other health care professionals on an as-needed basis. The goal of supported living is to assist with basic needs while encouraging independence, engagement, and activity.

When evaluating a supported living arrangement, look closely at the cost, as most arrangements are privately operated and must be paid for out-of-pocket. It is important to determine if the support services required are included in the daily cost or if they are additional charges. If considering a supported living arrangement and finances are a factor, it is important to apply for the Medicaid Home and Community-Based Waiver Program and find a program early, as waiting lists can be long.



Advantages of a supported living arrangement

- a home- or apartment-like setting
- the possibility of personal care assistance and health care monitoring
- options of social and recreational programs
- transportation to appointments, shopping, or other personal business
- allows less restrictive living arrangements
- licensure and regulations by the state

Adult Foster Homes

Individuals with special needs may have the option of living with a family other than their own. The level of care within adult foster homes varies greatly. Most foster families receive state funding for their services and, as such, are required to follow state and local agency regulations. The state Department of Social Services website often provides information on state-accredited independent living options.

Group Homes and Community Residences

Group homes and community residences are professionally staffed facilities that offer supported living in a home- or apartment-like setting. This type of arrangement brings together a number of individuals with similar support needs. Individuals are typically employed, attend day programs, or participate in social, recreational, or skill-building activities. Staff living or working at these homes provide a range of services that vary by placement.

Residential Placements

Residential placements are long-term living arrangements for those who require extensive care or support around the clock. The availability and types of these placements vary greatly depending on the facility and the population they serve. In general, they are categorized as rehabilitative care centers, specialty care facilities, and nursing homes.

The Civil Rights of Institutionalized Persons Act (CRIPA) provides investigative ability to the U.S. Attorney General regarding the conditions of confinement at state and local government institutions for the purpose of correcting issues that seriously jeopardize the health and safety of its residents. A civil lawsuit may be initiated if conditions or treatment of the residents are in violation of their rights.

Rehabilitative Care Centers

The focus of a rehabilitative care center is to provide short-term care and rehabilitative treatment to help develop the skills needed to move to a less restrictive environment. Services within a rehabilitative care center may include physical therapy, occupational therapy, speech or language therapy, counseling, and medical support.

Specialty Care Facilities

Specialty care facilities focus on the care of individuals with specific conditions or those with more severe mental, emotional, or medical conditions. These facilities typically provide longer-term care, a more intensive level of supervision, and around-the-clock medical support. Services vary by facility, and are dependent on the conditions addressed.

Nursing Homes

Nursing homes are long-term care facilities for those who are no longer able to care for themselves due to severe medical conditions. Some nursing homes are suitable for those with severe cognitive impairments, however, when determining the appropriateness of a nursing home placement, the individual's age and type of impairment must be carefully considered. Services focus on long-term medical care and support, though some facilities may offer short-term or respite care services.

Note: In some cases, young people who have no other community living options may be referred to nursing homes. In such instances, one should be aware that the schedules, activities, and staff may not be prepared to work with younger residents.

Well-Being

Healthy relationships help support emotional well-being. Individuals respond differently to managing an illness or disability and relationships can become more complicated. When seeking support and assistance from family and friends, it is important to be aware of and accept their limitations. Open communication between spouses, siblings, and children can provide opportunities to understand various viewpoints and needs which can often prevent communication problems from arising.

While family members may provide most of the emotional and physical support, it is also important to develop friendships and engage in activities outside of the family. Friendships often provide additional support and attention. The military lifestyle may pose challenges to developing and maintaining relationships. Friends can provide support when service members are geographically separated from their families. Friendships may change when families relocate. Even though there may be physical distance, support can be maintained through phone calls, emails, and other forms of electronic communication such as Skype, Facebook, blogs, or Twitter.

Personal Well-Being

Everyone faces continued and varied responsibilities and demands in everyday life. An illness or a disability, or providing for the care of another, can make these responsibilities and demands even more physically and emotionally challenging. While each life stressor may seem small or insignificant when viewed individually, these stressors eventually accumulate and affect the ability to cope, leaving the person exhausted, sad, or overwhelmed. People are much more likely to experience feelings of success and resilience if they are able to invest time in taking care of their own emotional and physical well-being.



Note: The diagnosis of an illness or disorder can be life changing. It may take some time to process the news. Feelings of denial, fear, anger, guilt, anxiety, confusion, and grief are all normal emotions and reactions to a new diagnosis. It is important to:

- Seek a second expert opinion if there are any doubts regarding the diagnosis
- Listen carefully, take notes, and ask questions
- Know what to expect regarding tests, treatments, medications, and the potential side effects
- Bring a family member or friend to appointments and consultations to provide support
- Talk to employers if time off from work is needed
- Consider counseling or support programs to help learn ways to cope with the physical and emotional challenges
- Learn everything possible about the disorder by reading books, going to lectures, and talking to doctors
- Get adequate sleep, nutrition, and relaxation

Prolonged periods of stress can adversely affect physical and emotional health. Renewing oneself involves taking breaks from daily living tasks and from the responsibilities of living with an illness or disability. Balancing personal needs with the needs of the family is important.

Compassion Fatigue

Compassion fatigue is a form of burnout that can occur when providing continuing care for someone with an illness or a disability. Those who find it difficult to maintain a healthy balance between their personal needs and their dedication to caring for others can experience compassion fatigue as physical, emotional, or spiritual exhaustion.

Although symptoms may vary, the following behaviors are often red flags:

anger	hopelessness
blaming habits	inability to maintain balance of empathy and objectivity
chronic lateness	increased irritability
depression	decreased ability to feel joy
diminished sense of personal accomplishment	low self-esteem
physical ailments	abuse of drugs, alcohol, or food
high self-expectations	

Compassion fatigue may be prevented or alleviated by:

being aware of and accepting limitations	finding outlets for relieving stress
taking short breaks throughout the day	developing relationships with others
organizing daily tasks and responsibilities	setting priorities
asking for help or taking a break when needed	

Counseling Services

Living with or caring for someone with a special need can be emotionally difficult at times. There may be situations that seem overwhelming and sharing some feelings, worries, or concerns with family and friends may not be possible. Having someone to listen who is not directly involved in the situation may be beneficial. Social workers, counselors, and psychologists can provide support and guidance to help both individuals and families improve coping skills. Access counseling services through Military OneSource, Military Family Life Consultants, Installation Family Support Centers, and TRICARE (www.tricare.mil—search "mental health and behavior").

Military OneSource

Military OneSource offers short-term, non-medical counseling options to active duty, Guard, and Reserve members and their families. They provide up to twelve sessions, per issue, per counselor, at no cost. Counseling sessions may be face-to-face, on the telephone, or online consultations. Services are designed to provide help with short-term issues such as adjustment to situational stressors, stress management, decision making, communication, grief, blended-family issues, and parenting skills issues. For additional program information, contact a Military OneSource consultant at 1 (800) 342-9647.

Personal Safety

Compared to the general population, individuals with a disability are more likely to be taken advantage of, emotionally harmed, or to be victims of a crime. It is important to keep safe physically, emotionally, and financially. Personal safety classes are offered through local police departments, disability offices, or community recreation centers.

Personal safety can be enhanced by taking precautions such as:

- choose, use, and maintain the correct adaptive equipment, such as canes or wheelchairs
- guard personal and financial information
- set appropriate personal boundaries with strangers, acquaintances, caregivers, friends, and family
- avoid alcohol or illicit drugs that impair the ability to make decisions
- be aware of surroundings at all times
- avoid places that appear inaccessible or that may require someone to help with access
- act calm and confident in public situations
- avoid troubled, dark, or unpopulated areas

- use caution and stay alert while using public transportation or traveling in unfamiliar areas
- know how and where to find help in any situation
- learn and practice self-defense skills
- carry a cell phone with easily accessible local emergency and police numbers
- report any questionable or illegal actions

Emergency Preparedness

Emergencies can happen without warning. Being prepared improves the ability to respond, cope, and recover from a situation that catches a family off guard. Planning for an emergency can be essential for military families as they often live apart from the support of close family and friends. For emergency planning and preparedness information, check with the local installation.

Military family members may reside in areas that require evacuations. Depending on the illness or disability, additional preparations may be needed in the event of an emergency. The installation and the local community have disaster preparedness plans. Familiarization with these emergency plans can help. The Federal Emergency Management Agency (FEMA) (www.fema.gov), Disability.gov (www.disability.gov), and the American Red Cross (www.redcross.org) have resources to help develop family emergency plans. Specific information on military family preparedness can be found at FEMA's Ready.gov website (www.ready.gov/considerations/military-family-preparedness). Once a plan has been developed, create an emergency preparedness kit.

Emergency Response Systems

Being able to access emergency services can be a critical concern especially for individuals who are often alone. Technology is available to improve safety and independence within the home between visits by family members or professional caregivers. This technology can be particularly helpful to individuals who have difficulty exiting a home by themselves or if other members of the home are unable to assist in an emergency situation.

This type of technology can assist with:

- communicating through video with family, friends, or caregivers
- calling for help in the event of an accident or emergency
- monitoring an individual's location and safety if they tend to wander or forget where they are

Emergency Services

Whether living on the installation or in the community, it is important to notify the local fire department or police station regarding any conditions or medical needs a family member may have. Information regarding the disability, medications, and needs can be placed on file in the event that assistance is required. Many local fire or police departments offer generators to individuals who have power-dependent medical equipment. Keep local emergency contact information accessible.

Service Animals

Under the Americans with Disabilities Act (ADA), service animals trained to provide assistance to an individual with a disability are not “pets” and should be allowed into emergency shelters. Some states have also passed laws pertaining to accessing emergency evacuation facilities and shelters with an animal. Owners should include their service animals in any emergency plans, whether it is taking the animal to the shelter or making other arrangements for its care. Emergency kits should include specific items for the care and feeding of any service animals, along with licenses, rabies tags, or specialty equipment such as harnesses. The DisabilityPreparedness.gov website (www.disability.gov—search “service animals”), the American Red Cross, and various animal-related organizations have additional tips for emergency preparedness for service animals, including detailed supply lists for an emergency preparedness kit.



Military Aid Societies

At times, emergencies can cause unexpected financial and personal consequences. Additional support can be found through organizations affiliated with the military Services. Relief societies exist to help service members and their families with unexpected problems or financial emergencies. Relief Societies may provide assistance for:

- emergency transportation
- funeral expenses
- disaster relief assistance
- child care expenses
- essential vehicle repairs

- food, rent, and utilities
- medical/dental bills

Each military Service is supported by a private, nonprofit charitable organization that provides emergency financial assistance:

- Army Emergency Relief (www.aerhq.org)
- Navy-Marine Corps Relief Society (www.nmcrrs.org)
- Air Force Aid Society (www.afas.org)

Transportation

Transportation is necessary for work, medical care, and recreational and social opportunities. Sometimes modifications can be made to personal vehicles to make driving easier for someone with a disability. Options range from lower-cost adaptations such as remote lock/entry, transfer bars, steering aids, and swivel seat cushions to fully modified vans with wheelchair access and electronic lifts. Whether using a personal vehicle or deciding to take public transportation, proper planning is important. Knowing the best routes to take and planning for adjustments to those routes in the event of traffic, weather, or changes to a routine can make travel easier for individuals with disabilities. Keeping current maps, timetables, and schedules can assist with unplanned issues that may arise. Using an AT item, such as a global position system (GPS), or a phone-based Internet mapping service can help when travel plans change.

If a disability limits mobility or creates a safety concern in parking lots, obtain a handicapped placard or license plate from the Department of Motor Vehicles. These placards and plates allow the use of special reserved parking spaces. However, if the disability or injury is temporary, there is a limit to the amount of time placards can be used.

After her accident, Kathy found it difficult even to come home from the hospital in their small sedan. The family got a van, modified for Kathy's needs, including hand controls for the gas and brakes, and a knob on the steering wheel. The van has a backup camera and a remote-controlled system to open the side door and lower a ramp for easy entry by wheelchair.

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Notes



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Introduction

Introduction to Module 6

Community participation is vital to living a well-rounded and happy life. The benefits of actively engaging in the community through various programs can help improve physical and emotional health. Activities offer an excellent opportunity to find and develop informal support groups. Some activities are designed specifically for people with special needs and can offer programming designed for individuals with varying capabilities.

Finding the Right Activity



Accessible trips, outings, classes, and physical fitness activities can be found on the installation or within the local community. No matter what the interest is, most commercial businesses and activities are accessible. Many entertainment venues assist those with special needs, for example, meeting certain dietary requirements or providing reserved seating. Calling ahead to arrange accommodations will help the venue meet any special needs, allowing for a more enjoyable activity.

Kathy and Mike recently took a cruise to the Bahamas. They chose a ship that was wheelchair accessible and provided personal assistance. The time they spent planning paid off. Kathy was able to fully enjoy the vacation and Mike could relax and enjoy a brief respite from his caretaking role.

Parks and Recreation Activities

Most communities offer parks and recreation activities to those living in or around their area. Most are operated by local city or county offices and offer a wide variety of programs and activities. The National Park Service website (www.nationalparks.org) provides information, maps, and travel tips on almost 400 national parks. This includes information on accessibility and availability of special resources for individuals with special needs. Accessibility within public and national parks often include the park areas, beaches, and picnicking areas, as well as rental cabins.

Athletic and Sports Programs

Athletic and sports programs can be found through the county or city parks and recreation programs. Many feature activities such as golf, bowling, and basketball. Some programs offer sports specifically designed and accessible to individuals with special needs. Explore nationally supported programs, such as Disabled Sports USA (www.dsusa.org), the National Wheelchair Basketball Association (www.nwba.org), and the National Center on Physical Activity and Disability for athletic and sports programs that may be sponsored locally.

Hobbies and Crafts

Hobby and craft activities can often be found through local community colleges, parks and recreation programs, or other public and private venues. Knitting, painting, auto mechanics, and photography are just some of the activities found in the local community. For additional information on specific hobbies or crafts, search the Internet for national or local clubs.

Art Programs

Adults with special needs can choose to participate in activities that are available to everyone in the community. Some activities are managed and directed by people with special needs at both the national and local level, for example, The National Arts and Disabilities Center (www.semel.ucla.edu/nadc) or The Very Special Arts (www.kennedy-center.org/education/vsa).

Travel

Adults with special needs may have many opportunities to travel; however, be careful to ensure that transportation, accommodations, and destinations are accessible. There are travel agencies specializing in tours that accommodate those with varying needs. Some tour groups offer special tour guides or allow companions to travel at reduced rates.



Some general health and fitness tips include:

- consult a physician prior to increasing activity levels
- ask for assistance at the facility regarding accommodating special needs
- set realistic and attainable goals, and revisit/update as necessary



Morale, Welfare, and Recreation (MWR) programs are offered by all branches of Service and provide a variety of leisure programs on and off the installation, including fitness and sports, libraries, skill development programs, travel and lodging, and recreational programs. Visit MilitaryINSTALLATIONS (www.militaryinstallations.dod.mil) for a complete listing, with maps and directions.

Volunteer Programs

A number of benefits are associated with volunteering, including learning new skills, developing valuable work experience, making new friends, and gaining leadership skills. Volunteer opportunities can be found throughout the local community at schools, libraries, hospitals, and many nonprofit groups. The Corporation for National and Community Service (www.nationalservice.gov) offers a listing of volunteer opportunities throughout the United States.

Religious and Spiritual Programs

Religious and spiritual programs offer a way to worship, socialize, and volunteer. Spiritual leaders and members can offer encouragement and friendship. Spiritual communities welcome individuals who are seeking support and have useful resources to share, including participation in various programs, recreational outings, volunteer opportunities, and other activities that may be of interest.

Fraternal Organizations

Fraternal organizations are made up of people who share a common vision. Well-known fraternal orders include the Knights of Columbus, Lions Club International, Optimist International, and The Benevolent and Protective Order of Elks. Many fraternal orders serve mainly as charitable institutions and social centers.

Disability-Specific Organizations

Sometimes it is more comfortable and helpful to interact with people who have the same special needs and face similar challenges. Many disability-specific organizations have local community chapters or websites offering blogs, newsletters, and the latest information related to the special need. For example, the Learning Disabilities Association of America (www.ldanatl.org) provides information for people who have learning disabilities and their family members, and the Epilepsy Foundation (www.epilepsyfoundation.org) does the same for those managing epilepsy.

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Introduction

Introduction to Module 7

Continuing education and employment offer opportunities for increasing independence and financial security. Many options exist for individuals with special needs to continue their education and improve their employment opportunities. Resources to promote self-sufficiency exist on the national, state, and local levels, and some include financial assistance programs to help with training.



Educational Options

Adults with special needs can benefit from continuing education both as a way to open doors to employment and as a way to develop in a social and educational setting. Vocational classes, college certificate programs, apprenticeships, and college classes can enhance the ability to secure meaningful employment and pursue personal interests outside the home.

Educational Paths

Finding a good match between interests and a career is often the best place to start. Begin by thinking about areas of special interest, aptitudes, and values. Use available online career assessment tools or state employment or vocational rehabilitation agencies to explore educational and career options to determine individual interests and strengths. Knowing preferences towards working with people, things, or data can help identify a potential career area and provide the motivation for success.

Identifying career interests also involves investigating the scope of a career, such as working conditions, required education, and potential salary. The Bureau of Labor Statistics (www.bls.gov) and the Department of Labor (www.dol.gov) provide helpful statistics for evaluating areas that expect job growth. To get a better understanding of actual job requirements and working conditions, it is often helpful to talk with people who currently work in the field of interest.

It is important to check on any Medicaid Waiver services being received before choosing to attend an out-of-state program. If there is no reciprocity agreement between the state providing the benefits and the state the recipient is moving to, the waiver and provided services will likely be discontinued.

Exploring the training or educational programs needed to achieve a career goal can take some time. Public libraries often have information regarding local colleges or training programs. State and county websites often maintain listings of available educational resources. For those who require more intensive support, colleges and universities that offer specific programs for individuals with special needs may be an effective choice.

When deciding upon an educational program ([see the Educational Paths Addendum, A:1](#)), it is important to examine the admission standards of all the schools being considered. All students must meet the basic requirements for admission and must be able to complete the application process. Most colleges have deadlines for submitting admission applications and financial aid packages. To maximize opportunities, it is important to meet deadlines and application dates. Helpful information about the application process and financial aid are available at the HEATH Resource Center (www.heath.gwu.edu), which is a national clearinghouse on post-secondary education for individuals with special needs.

If planning to attend classes or programs away from home, student housing options will need to be considered. If housing is provided to students without a disability, a post-secondary school must provide accessible housing at comparable costs to students with disabilities. When planning on relocating, carefully evaluate the resources and services available in the new community. Not all communities offer the same programs and services. Any public benefits or health care benefits currently received may be impacted by attending a school out of state.

Proprietary (for profit) post-secondary schools offer a variety of programs such as medical technician training, truck driving, and information technology. While these schools may be attractive because of their career focus, keep in mind that these schools often do not provide the assistance or support to those with special needs that can be found at local schools.

General considerations when choosing a post-secondary education program include:

- What is the total cost of attendance (tuition, books, and materials; lab fees; housing; and other fees)?
- Is the level of debt incurred for attending the program feasible?
- Would a community college be a viable option as an initial first step?
- Would a large school or a small school be better?
- Are scholarships or other payment options available?
- Does the program offer the kind of support needed, such as a Disability Student Services (DSS) Office?
- What documentation is needed to qualify for support services?
- Is the program near family or other support systems?

For additional information on choosing a school, visit the Department of Education website's (www.ed.gov/) section about colleges and technical schools.

Adult Continuing Education

Many local school districts offer adult education courses that include basic education, English language skills, and specific vocational skill training. Courses are offered in the evening at local schools and are affordably priced. Local community colleges provide courses to support adult education, including test preparation, business, finance, computers, and parental education. Local libraries or online searches can assist in obtaining information regarding workforce development and continuing education programs.

Trade and Technical Schools

Trade, technical, or vocational programs tend to be shorter than academic degree programs and focus on specific occupational skills. While programs differ, most provide paths to skill certification or certificates of completion. Some of these programs offer associate degrees in addition to skill certificates. These programs tend to be geared towards those who want employment in career fields such as health care, hospitality, or technology. For additional information on finding a trade or technical school, visit the Federal Trade Commission's Facts for Consumers Choosing a Career or Vocational School website (www.ftc.gov—search "vocational schools") or the Association for Career and Technical Institute website (www.acteonline.org).

Apprenticeship Programs

Apprenticeship programs offer an opportunity to learn a trade while earning money. In this type of employment, individuals learn to do a job from a professional or expert in the field.

Apprenticeship programs are offered in trades that tend to be more hands-on, such as construction, air conditioning, plumbing, or carpentry.

Apprenticeship programs offer students who have completed their secondary career, technical education or community college education the opportunity to begin working in their chosen field. Participating in an apprenticeship program can help a worker progress up the career ladder. Apprenticeship programs that lead to licensing are offered by some organizations and unions.



Each military installation has an Education Office that provides information on academic programs, financial aid, and scholarships. The Education Office can help with researching careers of interest, finding academic programs, and prioritizing options. Installation Education Offices can be found by visiting Military INSTALLATIONS (www.militaryinstallations.dod.mil).

A comprehensive list of community colleges, listed by state, is offered through the University of Texas at Austin (www.utexas.edu/world/comcol/state).

Questions when considering an apprenticeship program

?	Is a high school diploma a prerequisite?
?	How long does the apprenticeship last?
?	What pay can be expected while in the program?
?	After the apprenticeship is completed, what jobs are offered?
?	What other levels of hands-on and classroom training are possible after the apprenticeship ends (e.g., journeyman)?
?	What employment assistance is available?

Community Colleges

Community colleges offer a wide range of continuing education as well as degree programs. Most community colleges offer the opportunity to enhance one's skills, complete a career certificate, or earn an associate degree. Many schools offer pathways to a four-year college or university. Many also offer a variety of technician training programs and certificates. Community college is an economical choice for those who are beginning or changing a career path. Classes are offered throughout the day and into the evening to fit into most schedules. For additional information regarding community colleges, visit the installation's Education Office or the American Association of Community Colleges website (www.aacc.nche.edu).

Four-Year Colleges and Universities

Four-year colleges and universities offer educational programs that lead to bachelor's, master's, or doctoral degrees. Students attending a four-year program are required to choose a course of study or major. All four-year colleges require general education courses (i.e., English, math, and science), as well as classes required within a chosen major. Comprehensive information and web links about post-secondary education and training for students with special needs can be found at the HEATH Resource Center website (www.heath.gwu.edu).

Self-Disclosure and Accommodations

Section 504 and the Americans with Disabilities Act Amendments Act of 2008 (ADAAA) require colleges to provide reasonable accommodations to make their programs accessible to students with special needs. It does not legally require colleges to identify students with special needs. It is the student's responsibility to self-identify and seek the support and services needed.

When self-identifying, appropriate documentation must be provided regarding the special need and the college's procedures for requesting accommodations must be followed. One must expect to self-advocate for specific needs and requirements. Once identified as having a need for accommodation, it will be up to the individual student to discuss specific needs with each professor.

Some commonly requested accommodations at post-secondary schools include:

- writing labs
- note takers
- audiotape lectures
- extended time to take tests or complete assignments
- distraction-free testing areas
- special interpreters (i.e., sign language interpreters)
- reduced class/credit load

Many community and four-year colleges today allow students to download lectures onto iPods, smart phones, or computers. Also, many instructors and professors use electronic files and platforms such as Blackboard to reinforce learning opportunities.

The Disability Student Services Office

Prior to finalizing a decision about a post-secondary school, it is worthwhile to visit the school's DSS Office. This office can provide information regarding the school's programs and support services, and specific information about how they would be able to meet an individual's needs.

It is essential to contact the DSS Office once accepted to the school, as it can be a valuable resource in locating services and support. Self-advocacy, accommodations, and student assistance can make the difference between educational success and failure.

Scholarships

State vocational rehabilitation services offer financial support for post-secondary education to qualified individuals. To find a state vocational rehabilitation services office, visit Military OneSource's (www.militaryonesource.mil/efmp) family member education scholarships or state resources.

Foundations and organizations sometimes offer scholarships to individuals seeking to continue their education. Special-needs-specific organizations can be a good place to find scholarships. The HEATH Resource Center (www.heath.gwu.edu) provides a comprehensive listings of scholarships available to those with special needs.

For additional information on Section 504 and ADA rights and responsibilities, visit the Office of Civil Rights website (www2.ed.gov).

Visit the Equal Employment Opportunity Commission website (www.eeoc.gov) for additional information on the ADA and employment.

Employment

Whether seeking employment in an area of interest for the first time or looking to retrain for a new career, there are a number of laws that protect the rights of people with special needs in employment. In addition, there are programs and services to assist in finding and maintaining employment.

The Americans with Disabilities Act

Individuals with a special need should be aware of their rights and responsibilities when entering the workforce. The Americans with Disabilities Act (ADA) is a federal law that establishes equal employment opportunities for a qualified individual seeking work. The ADA provides equal work opportunities by requiring employers with more than fifteen employees to make reasonable accommodations for otherwise qualified applicants with special needs. For assistance, contact the ADA Technical Assistance Center (<http://adata.org>) at 1 (800) 949-4232.



Disclosure and Accommodations

Employers may not ask about a special need. It is up to the individual to disclose the special need and provide the needed supporting documentation. When choosing to disclose a special need, be prepared to describe any accommodation that will help in the performance of the job. Reasonable accommodations are generally no- or low-cost solutions that the employer can provide to remove barriers that may exclude someone from employment. The employer is not required to provide a reasonable accommodation if it imposes an undue hardship based upon the difficulty or expense of the accommodation when compared to the employer's size, financial resources, nature, or structure of the business. For additional information about accommodations, visit the Job Accommodation Network (<http://askjan.org>).

Discrimination in the Work Place

The Equal Employment Opportunity Commission (EEOC) is responsible for enforcing federal laws that prohibit employment discrimination due to race, color, religion, sex, national origin, age, or disability.

Any charge of discrimination must be filed with the EEOC within strict time limits and must be done before a job discrimination lawsuit can be filed against an employer. The EEOC evaluates the complaint to determine if it is covered under federal laws. The coverage depends on the type of employer, the number of employees it has, and the type of discrimination alleged. Discrimination may include:

- unfair treatment
- harassment by managers, coworkers, or others in the workplace
- denial of a reasonable workplace accommodation
- retaliation because of a job discrimination complaint, or assistance with a job discrimination investigation or lawsuit

Additional information on workplace discrimination can be found at the EEOC website (www.eeoc.gov).

Community-Based Employment Options

There are a number of potential employment options to explore within the community. Each option offers a different level of support. To find an appropriate fit, it is helpful to focus on individual interests and abilities. Most employment falls into the categories of competitive employment, self-employment/entrepreneurship, supported employment, mobile work crews, sheltered workshops, and day activity centers.

Competitive Employment

The goal for most individuals, with or without special needs, is to find competitive employment that can help them sustain a comfortable and satisfying quality of life. Competitive employment means work in the local labor market, whether full-time or part-time, that is compensated at or above the minimum wage. Competitive employment benefits the employer and the individual employee: the employer gets a good worker, and the individual earns a competitive wage. Competitive employment is possible for many individuals with special needs, especially if provided appropriate training and accommodations.

Self-Employment/Entrepreneurship

A particular interest or a work preference may lead to the consideration of self-employment options. Many adults with special needs become small business owners by establishing a business in an area in which they are knowledgeable. Entrepreneurs are growing in numbers as people seek to fill the needs of a changing economy. Assistance for starting a business can be obtained via one of several federal government websites, such as Disability.gov (www.disability.gov) or the Department of Labor's Office of Disability Employment Policy (www.dol.gov/odep).

Information about disclosing a special need can be found by reading *The 411 on Disability Disclosure: A Workbook for Youth with Disabilities* (www.ncwd-youth.info/411-on-disability-disclosure). Although it refers to youth with special needs, the information is useful for all ages.

Michael enjoyed working but found the traditional business setting challenging. He and his family decided to start a vending machine business. With support from a personal assistant, Michael stocks and collects money from vending machines in various locations in town.

Supported Employment

Supported employment is designed to provide hands-on training and ongoing support to adults with special needs as they master a specific job. Trained staff, called job coaches or employment representatives, assist with teaching skills and behaviors required for specific jobs, find positions that meet individual needs, and provide support during the hiring process. The goal for people involved in supported employment is to gain long-term, competitive employment. Additional information on supported employment can be located through the state Department of Vocational Rehabilitative Services or by visiting the Council on Vocational Rehabilitation (www.parac.org/svrp.html).

Jenny has limited literacy skills, but her job coach approached a university about carving out a job for her. She sorts mail, stocks supply closets, shreds documents, and helps with deliveries. This allows the receptionist to focus on other tasks while Jenny develops workplace skills.

Mobile Work Crews

Mobile work crews are often specifically designed to employ individuals with special needs. Most are small groups of employees who travel from one location to another performing certain tasks, such as cleaning or grounds maintenance. Mobile work crews provide the opportunity for paid employment in a variety of community settings and provide the benefit of on-site trained supervisors. Mobile work crews are typically funded through the Department of Vocational Rehabilitation, Medicaid, or local community programs.

Sheltered Workshops

Sheltered workshops assist individuals who are not ready to work without supervision. These types of programs are typically segregated from the community and may or may not include vocational training. Most sheltered workshops are operated through private, not-for-profit organizations and funded by a variety of state and federal sources.

Day Activity Centers

Day activity centers provide a supervised, structured environment where participants can develop employment skills while strengthening daily living abilities. Individuals attending these centers may be able to move towards other supported or competitive paid employment. Medicaid is the primary payer for day activity programs.

Employment Assistance

Several agencies and programs exist to provide information and support when seeking employment opportunities. The The Office of Disability Employment Policy (www.dol.gov/odep) provides information and links to national, state, and local employment assistance for adults with special needs. Various resources are available to assist in finding employment.



Military OneSource's spouse employment section (www.militaryonesource.mil/seco) provides answers to many frequently asked questions regarding employment.

Installation Employment Assistance Program

An installation's employment assistance program is designed to help individuals reach their employment and career goals. This program, which has a slightly different name in each of the Services, can provide the tools and skills necessary to identify and actively pursue employment that matches individual needs and skills.

Military OneSource

Military OneSource (www.militaryonesource.mil) can help support personal, educational, and career goals by identifying local resources and performing a local search for employment agencies that specialize in personal career interests. Links to appropriate newspapers and websites that advertise job opportunities are also provided. Additionally, the website includes articles and resources related to finding a job and building a career.

Networking

Employment opportunities are often found through family, friends, community members, or even frequented businesses. Local business owners may be able to assist a job seeker by providing an introduction or job opportunity in their own or a related business. Social networking sites such as Facebook and LinkedIn can be used to find employment opportunities, connect with others, and share advice.

Note: Caregivers can help individuals with special needs recognize how their strengths and limitations fit with employment options, discuss the pros and cons of employment opportunities, and think about how they can be successful as employees.

Vocational Rehabilitation Services

An adult with a special need may be eligible for services from the state Vocational Rehabilitation (VR) Services office. While the costs and access to services vary by state, most VR services are free or offered on a sliding fee scale. A vocational assessment can be completed to determine strengths, needs, skills, and interests. Once these are identified, the adult and their VR counselor develop an Individual

SOAR describes specific helpful accommodations, including raising desks to accommodate wheelchair users and digitizing written directions to smart phone applications.

Plan for Employment (IPE) which will include educational or training and employment goals, supports needed to achieve those goals, and estimated time frames for achieving them. It is important to remember that services are prioritized based upon the severity of the special need and the impact it has on the individual's ability to function and work. VR services can be located through the State Resources section on Military OneSource (www.militaryonesource.mil/cfmp).

CareerOneStop Centers (www.careeronestop.org) provide either brief or intensive employment services including job training and education. Disability Program Navigators assist in accessing employment opportunities and benefits. This service provides job search and placement assistance, labor market information, skills and needs assessments, and follow-up to help maintain employment. Some centers may offer more intensive services such as comprehensive assessments, individual employment plans, group and individual counseling, case management, and short-term pre-vocational services.

State Employment Agencies and Workforce Commissions

Free assistance with job searching is available at the local or state Employment Agency or Workforce Commission. This agency specializes in job seeker and employer services, unemployment benefits, employment training services, and job market information. The staff may offer assessments to determine interests, skills, aptitudes, and abilities, and provide a match to possible employers. Personnel at these agencies also help complete applications and refer applicants to job interviews.

The Job Accommodation Network

The Job Accommodation Network (www.askjan.org) provides information on accommodations for employers, employees, and future employees. The site includes information on interviewing, résumé, and tips on self-disclosure, as well as a Searchable Online Accommodation Resource (SOAR) (askjan.org/soar). SOAR is a useful tool to help explore specific accommodations that may be helpful at work, school, or home.

Career Opportunities for Students with Disabilities Career Gateway

Career Opportunities for Students with Disabilities (COSD™) is a professional association made up of more than 600 colleges and 500 different employers from across the country. Services include a nationwide online job posting and resume database specifically for college students and recent graduates with special needs. Students use Career Gateway (www.cosdonline.org/cosd-career-gateway) as a tool for identifying employers who are committed to including special needs as part of their diversity efforts. There is no charge for students to register or for employers to post available jobs, internships, and/or co-op opportunities.

Work Incentive Planning and Assistance Programs

For those receiving benefits from the Social Security Administration (SSA) (www.ssa.gov), the Work Incentives Planning and Assistance (WIPA) (www.ssa.gov/work/wipafactsheet.html) Program can help evaluate how employment will impact SSA benefits and eligibility for employment incentive programs.

Plan to Achieve Self-Support

The SSA also offers the Plan to Achieve Self-Support (PASS) program (www.socialsecurity.gov/ssi/spotlights/spot-plans-self-support.htm), a personal employment plan that helps individuals set aside income or resources for a specific period of time to achieve a work goal. When using PASS, the SSA does not count money set aside when determining Supplemental Security Income (SSI) (www.ssa.gov/ssi) payment amounts, thus allowing a potentially higher SSI payment to the individual. More information and applications can be found at the local SSA office.

Ticket to Work

Ticket to Work (www.chooseworkttw.net) is a voluntary program offered to individuals who receive Social Security Disability Insurance (SSDI) (www.ssa.gov/disability) benefits. It is provided as a means to increase independence by helping an individual work while continuing to receive SSA benefits. The Ticket to Work program removes many of the barriers that previously influenced people's decisions about going to work.

Under Ticket to Work, the SSA provides a ticket that can be used to obtain employment-related services from a group of organizations called Employment Networks (ENs). An EN can include CareerOneStop (www.careeronestop.org), VR, employers, and several other public and private agencies.

Impairment-Related Work Expenses

For those receiving SSDI, a specific amount of money can be deducted for impairment-related work expenses (IRWE). Examples of impairment-related expenses include wheelchairs, certain transportation costs, and specialized work-related equipment. For those who receive SSI, the IRWE is excluded from earned income when the SSA figures the monthly SSI benefit amount.

Financial Assistance

When a special need impacts the ability to hold gainful employment, it may become difficult to maintain financial independence. Public benefit programs may be able to supplement or replace some the lost income. If a special need is limiting a person's financial independence, SSI, SSDI, and the Supplemental Nutrition Assistance Program (SNAP) are three programs that can help.

Visit www.benefits.gov to find out more about Medicaid or other government programs.

Supplemental Security Income

SSI is designed to provide financial support to those whose special needs impact their employability and for eligible adults who are blind, disabled, or over the age of sixty-five. The basic SSI amount is the same nationwide, though some states supplement the federal benefit amount. The amount is adjusted yearly for cost of living. SSI helps meet monthly living expenses and automatically qualifies a beneficiary for the Medicaid health benefit in some locations.

Those needing assistance can apply for SSI (www.ssa.gov/pgm/ssi.htm) through local SSA offices at any time. It is recommended that this process is started as soon as qualifications are met, as waiting periods to process final disability and income eligibility determinations can vary.

To be eligible for SSI, the following requirements must be met:

- have a diagnosed physical or cognitive impairment that results in the inability to do any “substantial gainful activity”
- have a special need that has lasted or is expected to last at least twelve consecutive months, or is expected to result in death
- hold United States citizenship, or meet certain requirements if a noncitizen
- have not left the country for more than thirty consecutive days
- have met financial eligibility requirements in regard to income, assets, and resources

Social Security Disability Insurance

Those who have worked for a certain period of time before becoming disabled can access a cash benefit program known as Social Security Disability Insurance (SSDI) (www.ssa.gov/disability). Eligibility is based on work history. The amount one is eligible to receive is based on age and the number of years worked. If one is eligible for SSDI, one is automatically qualified for Medicare benefits. SSDI pays only for total disability. No benefits are payable for partial disability or short-term disability. One can receive SSDI payments and continue to work with some restrictions. Applications for SSDI (www.ssa.gov/applyfordisability) can be made at any time through the local SSA office or online through the SSA’s website.



Military Families and SSI Availability Overseas: Most people who receive SSI and leave the United States for thirty days or more are no longer eligible for SSI. However, children may continue to get SSI benefits or apply for benefits while overseas if they are citizens of the United States and living with a parent who is a member of the Armed Forces assigned to permanent duty anywhere outside the United States.

Supplemental Nutrition Assistance Program

Most grocery stores and commissaries participate in the Supplemental Nutrition Assistance Program (SNAP) (www.socialsecurity.gov/pubs/10100.html), the federally funded, state-administered cash benefit program formally known as the Food Stamp Program. The program enables low-income families to buy certain food items with an Electronic Benefits Transfer (EBT) card.

Health Care Assistance

A special need can often create a need for long-term medical care and support. This type of care can be expensive, especially when combined with a limitation or inability to maintain sufficient employment. While TRICARE can meet many medical needs, there are two government programs—Medicaid and Medicare (www.cms.gov/SpecialNeedsPlans)— that may be available to provide additional benefits.



Medicaid

Medicaid (www.medicaid.gov) is a federal- and state-funded medical assistance program that can help cover basic health and long-term care services. It is especially beneficial for those with significant special needs, as it is often the primary or only payer for adult services and programs.

To be eligible for Medicaid benefits, certain requirements must be met, which may include age, pregnancy status, special need, income and resource maximums, and citizenship/immigration status. Rules regarding

income and resources vary from state to state and from category to category. Even if one exceeds the income requirements, Medicaid may be available to persons with a special need if large medical or long-term care expenses are incurred and recipients are able to reduce their income through medical expense deductions.

Benefits.gov (www.benefits.gov) can be used to verify Medicaid or other government program eligibility. This information can also be located through a state's Medicaid agency. Military OneSource's Special Needs section (www.militaryonesource.mil/efmp) provides contacts to local Departments of Social Services or Human Services agencies.

TRICARE is always the primary payer if covered under both TRICARE and Medicaid.

Visit the SSA website (www.ssa.gov/pgm/medicare.htm) under the Medicare tab for an eligibility tool and information about Medicare eligibility and enrollment.

Home and Community-Based Services Waivers

Under Medicaid, the Department of Health and Human Services allows states to offer waiver programs for services. States have an option to determine which group of individuals with special needs qualify for which types of waivers. Military families most commonly seek out Home and Community-Based Services (HCBS) Waivers. These waiver programs enable the self-direction of some services to allow the recipient to live, work, and participate in the community. With the HCBS Waiver, the beneficiary specifies the nature of services, the provider of services, and the rate of compensation for the provider.

Individuals seeking an HCBS Waiver should apply as soon as possible, as the wait for services can be long. As these are state-based programs, relocation to a new state means the process of applying and waiting for a waiver begins again. Most HCBS Waiver programs typically cover a range of services:

- Personal care and assistance – activities of daily living, such as bathing, toileting, light housework, laundry, transportation, and money management
- Health-related services – skilled and unskilled nursing services such as tube feeding, catheterization, and range-of-motion exercises
- Specialty services – assistive technology, medical equipment and supplies, pre-vocational services, educational services, and supported employment services
- Adaptive services – home modifications (including ramps, widening doorways, retrofitting bathrooms and kitchens), and vehicle modifications (such as steering and pedal adaptations)
- Family and caregiver supports – respite services, training for caregivers, and home health services
- Case management and service coordination – access and coordination of services and supports within and across public and private agencies

Long-Term Care

Medicaid Long-Term Care Services (www.medicaid.gov—search "long-term care services") provides a wide range of services in a variety of settings to meet a recipient's health care needs. This coverage may be available if certain financial qualifications are met. Long-Term Care Services coverage usually requires limited income and assets. Some states require those who have extreme needs and high medical bills to reduce income to a state-set eligibility standard. Medicaid is frequently looked to as a resource for nursing home care. Nursing home residents who qualify for Medicaid must apply the majority of their monthly income, minus a small personal needs allowance, towards the cost of their care. Each state sets its own limits regarding the amount of income and assets spouses may keep for their own support.

Medicare

Medicare (www.medicare.gov) is a federally sponsored health insurance program designed to assist the elderly or disabled in securing reimbursement for some medical expenses. It reimburses costs for physicians, hospitals, and pharmacies, much like a private insurance company. Medicare is available for those aged sixty-five and older and for those with disabilities. Qualification for Medicare is based on the Medicare tax paid through employment; however, a worker's spouse, minor children, and adult children with disabilities may also qualify.

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Notes

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Introduction

Introduction to Module 8

⚠️ DISCLAIMER

Please be advised that the information in the legal section is not intended as legal advice. Laws may differ from state to state or change. The timeliness of information presented cannot be guaranteed. Consult the local Legal Assistance Office with any questions about a legal concern or specific situation.

When facing an illness or disability, routine responsibilities can begin to seem like major challenges. Managing daily responsibilities, medical appointments, and therapies becomes the priority, and planning for the distant future becomes something easily postponed. As difficult as it may seem to make the future a priority, it is nonetheless imperative to legally and financially prepare for the future regardless of the disability, illness, or life stage.

Why Planning is Important

Proper planning addresses all legal and financial issues that may impact an individual's future well-being. Planning can:

- reduce the stress associated with the unknown when a separation, disability, or death occurs
- ensure wishes are honored and affairs are managed accordingly
- arrange for the long-term support of one's self or family members
- alleviate the difficulty and guilt that occurs when people can no longer make decisions regarding their care

There are many documents and legal procedures that are commonly used or that can be helpful. Some of these are highlighted in this section.

Special Care Organizational Record

When planning for the future, information needs to be gathered to create records and legal documents in an organized fashion. The Special Care Organizational Record (SCOR) for Adults with Special Health Care Needs (www.militaryonesource.mil/efmp/special-care-org-records) is specifically designed to help track and organize medical, financial, and legal information in one central location. During times when the first priority is concern for medical appointments and requesting services, organized records allows an individual to quickly find needed files, share information with others, and provide necessary

There are some restrictions on how funds in a special needs trust can be used. Be sure to review the Special Needs Trust section for additional information.

care. In the event of a death, the executor of the estate may use the SCOR to locate information regarding personal papers, legal documents, insurance policies, benefits, banking and real estate information, keys, safe deposit boxes, and safes. Download or order a copy of the SCOR from Military OneSource (www.militaryonesource.mil/efmp/special-care-org-records).

Installation Legal Assistance Office

The installation Legal Assistance Office (www.militaryonesource.mil/legal) is available to provide a wide range of services. These services may be subject to availability of resources and the expertise of the Legal Assistance attorneys and tend to vary by Service and from installation to installation. Service members should contact the Legal Assistance Office at their installation with any questions regarding planning for the future. These offices can provide advice, information, and referrals.

Estate Planning

Estate planning is the ongoing process of directing assets to a specific person, arranging for the care of another, and reducing the tax liability on an estate. The most effective estate planning includes a combination of legal and non-legal documents that are reviewed at least annually or when circumstances change.

Letters of Intent

A letter of intent is a non-legally-binding document that provides written instructions regarding personal care or the care of family members in the event of the caregiver's absence, illness, incapacitation, or death. The letter of intent typically includes relevant background information, medical information, treatment needs, as well as informal information such as favorite activities, foods, and people to contact in the event of an emergency. It can also provide information about any plans in place for future living arrangements.

The information and insight found in the letter of intent will be especially important to the trustee for the [Special Needs Trusts](#). The trustee needs to understand the nature of the needs, day-to-day care, medical and family history, and any other details not covered by legal documents, especially those that may be less obvious to someone not directly involved in the day-to-day care. For example, the trustee will need to understand the medical care, personal needs, and any additional costs to budget and distribute funds.

The letter of intent often includes information such as:

- detailed description of the individual's personality, including difficulties and strengths
- preferences of the individual with special needs, including an explanation of wants and needs, favorite activities, and interests, etc.

- information regarding past locations, background information describing life experiences, living situations, and medical history
- activities of interest and their occurrences, including a list of daily, weekly, monthly, and yearly routines, activities, events, favorite locations and traditions
- reasons there is a need for a special needs trust—describe how the disability or illness impacts daily life and list ways to maximize support through available services or funding source

Wills

A will is the most significant document used in estate planning. If someone dies without a properly executed will, a probate or trial court will appoint an administrator of the estate and a guardian for any children. This situation also requires distribution of property in accordance with the state laws.

For those individuals who need or may need public benefits to any degree, being named as a direct beneficiary could cause a loss of funds, services, or other assets. Creating a special needs trust can redirect funds protecting eligibility for other benefits, especially public benefits. [See Special Needs Trusts on page 8:4.](#)

The requirements for a legally valid will vary from state to state. It is important to seek legal advice while drafting and executing the will to ensure it meets all applicable state legal requirements.

Powers of Attorney

A power of attorney provides the ability to appoint a person to manage one's affairs. The power of attorney may give full authority or it may be limited to certain decisions or transactions. It is possible to elect to have the power of attorney in effect immediately upon signing or it can be delayed until a designated event occurs, such as deployment or a severe illness/disability.

In the event of incapacitation, it is critical to have a power of attorney in place before a person is incapacitated. Once the person is very ill or disabled, it may be determined that the power of attorney was created at a time when the person was not capable of making sound decisions and may be non-binding. A power of attorney will help avoid the process of appointing a guardian, which can be long and expensive and could leave someone's financial affairs unaddressed until it is completed.



Life insurance, pension plans, and retirement accounts payable directly to a named beneficiary are not governed by a will or probate proceedings. Additionally, property owned jointly with survivorship rights is not subject to a will or probate proceedings.

As state laws differ, it is important to always check with an attorney in the state in which the person appointed as the power of attorney is living to ensure the correct form is used and signed correctly.

Power of Attorney for Health Care

A power of attorney for health care is a written legal document that allows the designation of another person to make health care decisions. The named person must follow any instructions or wishes expressed and must consider the author's personal values when making decisions. While laws vary by state, the power of attorney for health care can in some states take precedence over any guardianship orders in all health care decisions, unless a court orders otherwise.

Advance Health Care Directives

Advance health care directives are legal documents that provide instruction regarding health care, should someone become unable to make his/her own decisions. Advance health care directives are important, as modern medicine has the means to keep a person alive, sometimes indefinitely, whether or not the care and treatment reflects that person's wishes. They also help to prevent the cost of the care and treatment from being financially and emotionally devastating to the family. When setting up an advance health directive, it is important to speak with family members regarding the person's wishes to ease the likelihood of any family disagreements regarding the directive.

The requirements of advance health directives and living wills vary by state. The most common types of advance health care directives are powers of attorney for health care and living wills.

Living Will

A living will is a set of written instructions that explain a person's wishes regarding end-of-life decisions. The living will becomes active in the event of mental or physical incapacitation with no realistic hope of returning to a normal life. This document allows communication of any wishes regarding the use of artificial life support systems and authorizes the physician and a designated person to disconnect life-sustaining equipment.

Special Needs Trusts

A special needs trust is a financial planning tool that is used to provide for the supplemental needs of a person with special needs while protecting eligibility for public benefits. They are discretionary trusts created for people with disabilities to supplement, but not replace, public benefits. This type of trust allows an individual with a disability to continue to receive Supplemental Security Income (SSI), Medicaid, Section 8 housing, and other public programs while benefiting from trust fund money. The SSI is designed to pay for food, clothing, and shelter. Medicaid will pay for medical bills. The trust fund can be used for all other needs identified in the trust document. The money from this trust can be used

to purchase special wheelchairs, handicap accessible vans, as well as to pay for a personal attendant, or recreational and cultural experiences. Contact Military OneSource at 1 (800) 342-9647 for a list of attorneys who are qualified to handle special needs trusts.

Guardianship and Conservatorship

Eighteen is considered the “age of majority” in most states. It is presumed that once this age is reached, the individual is capable of making personal decisions regarding health, finances, and the future. At that point, caregivers have no legal control over a person’s financial, educational, or health-related decisions, unless the person is deemed incapacitated and not competent to manage his/her own affairs by a court, and a guardian or conservator is appointed by a court.

Guardianship is an important consideration for parents of adult children with severe special needs, as they no longer have a right to make decisions for their children without

guardianship or another document that provides such authority. This can be critical for an adult child who is very ill or very disabled and requires nonemergency medical treatment or assistance obtaining or managing services and support.



At times, an individual’s decision-making capacity may be affected by illness or disability. Guardianship or conservatorship may be the best way to provide protection for someone who has difficulty making complex decisions, or for protecting a person from emotional, physical, or financial harm.

For an adult with special needs, the decision to seek guardianship or conservatorship should be weighed carefully. The process requires that both the individual and potential guardian go before a judge and explain why guardianship is needed. This can be a very emotional and difficult experience, requiring significant thought and focus on the family situation and the extent to which the adult with special needs requires help, especially in areas where independent function is still possible.

Consult with an attorney experienced in elder care or special needs who can provide information on the pros and cons of guardianship and conservatorship

and help explain the specific legal process and requirements as they vary from state to state. Sometimes medical personnel may know of an attorney or life care coach who can be helpful.

What It Means to be a Guardian

A guardian, or in some states the guardian of the person, is the court-appointed person responsible for overseeing the care of another individual. The guardian does not have to provide all of the services or daily help to the individual. Other family members or a professional caregiver can support the individual's daily care. The guardian does not have to personally provide funds for the care of the individual. The guardian is also not responsible to other persons, or third parties, for the actions or choices of the individual.

Although the role of the guardian may vary from state to state, the following are some of the basic duties found in most guardianship orders across all states:

- deciding where the individual will live, either in or out of state
- placing the individual in a hospital, nursing home, boarding home, or another residential placement if found appropriate. It should be noted that a guardian cannot commit the individual against his/her will to a mental health institution without going through the formal legal procedure for involuntary commitment
- managing all of the individual's care and comfort, including clothing, furniture, vehicles, and other personal effects
- overseeing the individual's medical treatment and care
- arranging for training, education, and employment
- organizing transportation needs

What It Means to be a Conservator

A conservator (also called the guardian of the estate or property) is an individual, corporation, or state agency appointed by the court to protect and manage an individual's finances or estate. A conservator may be appointed by the court if the individual owns real estate or has a substantial amount of money or property or needs assistance with investments. In some states, the court must also determine that assets will be wasted if not appropriately managed, or that they are needed for the care, support, and welfare of someone supported by the individual. The conservator is not legally obligated to use his/her own money or property for the individual's care or support.

Although duties and responsibilities vary from state to state, there are some court-identified responsibilities required of the conservator and can include:

- providing an inventory of the estate and accounting for all of the funds and assets
- spending money for the care of the individual's dependents or those in the individual's home who are unable to support themselves
- managing and investing excess property and money to provide a reasonable return
- buying and selling property, and borrowing money on the individual's behalf
- employing people, including lawyers, accountants, and investment advisors, to assist in the conservator's duties, and paying for those services from the individual's estate

Establishing Incapacitation

Guardianship or conservatorship will be imposed only if the court determines a guardian or conservator is required due to incapacitation. Although the definition of incapacity varies from state to state, it is generally defined as being unable to make or communicate responsible decisions regarding one's self or one's property. In some states, incapacitation can be met if someone is impaired due to a mental illness, developmental delay, physical illness or disability, chronic use of drugs, chronic intoxication, or another cause. The extent of the incapacitation can vary, and in most states guardianships may be full or partial, or limited both for the person and/or the property of the individual. Guardianships and conservatorships can also be for the rest of the individual's life, or they may be revocable if the person becomes able to manage his/her own affairs. The initiation of a guardianship or a conservatorship and the possible termination is determined and ordered by the court.

Detailed documentation from a physician, or several physicians, is needed to show that the individual is not capable of full or partial independence. An illness or disability alone is not sufficient reason for determining guardianship or conservatorship. Executing the appropriate legal documents before becoming incapacitated may be sufficient to meet the individual's needs.

Legal Process

Every state has its own legal process for determining incapacity and appointing a guardian or conservator. The major procedural steps followed in most states are similar, including a petition being filed, an investigation and hearing, and the decision on appointing a guardian. If one is appointed, the guardian of the person then makes decisions about the individual's life and well-being. The court may also appoint a conservator to make decisions regarding the finances and property. The same person can be both guardian and conservator or there may be a different person for each responsibility. More information can be found in the [Legal Process](#) Addendum.

Guardianship or conservatorship may not be necessary if the individual executed needed documents such as a living will, a power of attorney for health care, a durable financial power of attorney, or a living trust while he or she had the capacity to do so.

Relocating with Guardianship and Conservatorship

Before a guardian or conservator relocates out of state or overseas, the issues and laws that can impact guardian status should be researched. The Adult Guardianship and Protective Proceedings Jurisdiction Act (www.uniformlaws.org) has been adopted by many states. In those states, the incapacitation order may be recognized if the guardian notifies the originating court and registers the original guardianship order with the local court at the new location. If relocating to a state that does not recognize out-of-state guardianships or conservatorships, the legal process may have to be repeated.

End-of-Life Care

End-of-life care planning provides the opportunity to make decisions regarding a person's final days and funeral and burial preferences. Planning in advance provides peace of mind and relieves the family of having to make decisions at a very stressful time. End-of-life planning starts with an incredibly important discussion about the process of death.

Hospice

Hospice care provides dignity and comfort to the dying and support to their family members during the last six months of life. Hospice care is available to those who have been given a terminal, life-limiting prognosis and are no longer seeking a curative treatment. The focus of hospice is to improve the quality of a person's last days by providing information and support as well as symptom and pain management. Services are typically available twenty-four hours a day and are tailored to meet the needs of the individual and the needs of the family. Services may include physician visits, nursing care, counseling, medical equipment, supplies, medications, medical social services, physical and occupational services, speech and language pathology, and respite care. Hospice care can be provided in the home, at a nursing home, or in a hospital, and is covered by TRICARE, Medicare, Medicaid, and other private insurance.

If hospice care services are being provided off the military installation, it is important to ensure that local emergency medical services and law enforcement professionals are aware of the situation and wishes. If care is provided on a military installation, a meeting with local law enforcement, chaplains, military treatment facility (MTF) representatives, and the hospice service coordinator can ensure all parties understand the individual's wishes.



The Uniformed Anatomical Gift Act allows individuals to donate their organs to others or to science after they die. Organ donor cards are available from most state motor vehicle departments.

Final Instructions and Funeral Planning

Providing final instructions includes ensuring that all personal, legal, and financial business is in order. It is important that all legal documents are current and reflect the individual's wishes.

Once the appropriate legal documents are in place, it is imperative that those closest to the individual have a copy of the documents and the patient's wishes are discussed with family members. Even if this discussion is difficult, family members cannot honor wishes and preferences if they are not aware of what the individual wants at the end of his/her life. Comfort can be taken in knowing that this type of open conversation will reduce much of the grief, anxiety, and guilt the family members will face if they must act on a person's final wishes.

When ready, it is important to discuss the following areas:

- What type of care should be provided?
- How should the last days be spent and who should be there?
- Under what conditions would artificial life support be appropriate?
- What will the funeral and the services look like?
- What should the family do with the body?

If there are any concerns, the hospice care nurse may be able to assist with development of final instructions. A funeral director will take care of transporting the body, making logistical arrangements, obtaining certified copies of the death certificate, and placing obituary notices. They may also assist in filling out claims forms for Social Security survivor benefits, veteran benefits, and life insurance claims. More detailed information can be found in the [Final Care Addendum \(A:3\)](#).

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TRICARE hospice care emphasizes supportive services, rather than cure-oriented treatment, for patients with a life expectancy of six months or less. The benefit allows for personal care and home health aide services. For additional information, read the hospice care brochure available at the TRICARE website (www.tricare.mil-search "hospice care").



Notes

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Introduction

Introduction to Module 9

Most people's lives are more satisfying when they have a clear picture of what they want for themselves. Planning for the future creates goals and clarifies the steps necessary to achieve them. Often, a renewed feeling of hope comes from the process of planning and envisioning specific ways to move forward and overcome barriers.

When beginning to set goals:

- examine what life was like in the past
- think about the current situation in terms of likes and dislikes
- map out the future using both short- and long-term goals
- identify steps to achieve each of the goals

Benefits of planning include:

- creating a vision of the future
- gaining confidence to move forward
- focusing on opportunities

Planning helps people develop a map for their life journey, whether relocating or transitioning from the Service. It helps them identify available resources and take charge of their future. Sometimes, plans are interrupted by changes in health or

environment (such as moving or being transferred), in policies (such as reduced funding for programs), and in resources (such as program non-availability). When these changes occur, it is important to know who can provide support and help. Websites such as Disability.gov (www.disability.gov) and Military OneSource (www.militaryonesource.mil) can be a source for both general information and links to specific topics.



Moving Ahead

9

Jeremy has a traumatic brain injury, and his family was told that lifelong nursing home care was probable. However, Jeremy's family holds onto the vision they have for his future: his own home and a job in the community, surrounded by family and friends. They are working with his therapy team to make their vision a reality.

Note: Being a caregiver for someone with special needs requires recognizing there will be differences in expectations, dreams, and hopes for the future. The caregiver can help the individual determine what is realistic given the current situation, assist with creating a plan of action, and help provide an understanding of pros and cons related to goals. Discussing these issues is not easy and requires open and honest communication.

The Exceptional Family Member Program



The Exceptional Family Member Program (EFMP) supports military families with special needs through its three components: identification and enrollment, assignment coordination, and family support. Military members who have a family member (spouse, child, or other dependent) with a diagnosed physical, intellectual, or emotional condition that requires special medical or educational services must enroll in the EFMP.

Enrollment

The EFMP enrollment staff will determine if the individual with special needs meets enrollment criteria and supply the appropriate forms. They can also help gather the required documentation, submit the paperwork, and follow up on the enrollment process.

Although each of the military Services handles enrollment somewhat differently, there are some commonalities:

- Each Service uses the Department of Defense (DoD) forms DD2792 and DD2792-1
- Medical and educational personnel are consulted about availability of resources
- The DD2792 medical form is reviewed by medical personnel
- The DD2792-1 educational form is reviewed by educational personnel
- All information is confidential and private, and maintained on a need-to-know basis

Contact the nearest installation EFMP office to enroll. Visit MilitaryINSTALLATIONS (www.militaryinstallations.dod.mil) to locate the EFMP offices. Military personnel or family members can also pick up the necessary forms and receive help completing them at various offices. By Service, those are:

- Army – at the military treatment facility (MTF), ask for the EFMP
- Marine Corps – at Marine Corps Community Services, ask for the EFMP Caseworker
- Navy – at the MTF, ask for the EFMP Coordinators' Office
- Air Force – at the MTF, ask for the Special Needs Coordinator
- Electronic copies of the forms and additional enrollment information can be found on Military OneSource (www.militaryonesource.mil/efmp)

Benefits of Assignment Coordination

Enrollment in the EFMP allows the diagnosis, support, treatment, and any special accommodations the individual may require to be considered by the Service during the reassignment process. Assignment coordination is a confidential process that occurs when the personnel command requests medical and/or educational professionals to review an enrolled family member's documented needs to determine availability of services at a projected location.

Assignment coordination is important because access to appropriate medical and educational services may be limited, especially in overseas and remote locations. When assignment coordination occurs, family members receive the care and support they require and the service member can focus more clearly on mission-related responsibilities. Enrollment does not impact the sponsor's career, as it does not prevent reassignment, deployment, or other career-advancing requirements. Service members have the option to accept assignments where services for their family members with special needs are not available; however, this usually means that the service member must live apart from the family so that family member's needs can be met.

EFMP Family Support

EFMP family support assists families with special needs to identify and access programs and services. It includes, but is not limited to:

- information and referral for military and community services
- education and training about issues related to the special need



You can find a listing of installation EFMP offices by visiting MilitaryINSTALLATIONS. (www.militaryinstallations.dod.mil).

Military OneSource (www.militaryonesource.mil) can be especially helpful to National Guard and Reserve families who do not live near an installation, or to members who are geographically isolated. For more information, visit Military OneSource or call them at 1 (800) 342-9647 and ask to speak with a Special Needs Specialty Consultant.

- non-clinical case management, including Services Plans
- warm hand-offs to the EFMP at the next location
- referral to other Family Center providers

The following are Service-specific points of access for the Family Centers:

- Army – Army Community Service, EFMP Manager
- Marine Corps – Marine Corps Community Services, EFMP Caseworker
- Navy – Fleet and Family Support Center, EFMP Liaisons
- Air Force – Airman and Family Readiness Center, EFMP Coordinators

Relocation

Moving is an integral part of military family life. Relocation can involve transition from county to county, state to state, or country to country. Moving leads to changes in providers and support systems as well as to the established routines of daily life. With some advanced planning, the disruption caused by moving can be minimized.

“The battle is worth it,” Wesley noted, saying that persistence and perseverance are important qualities. It is easy to get frustrated with all the steps required. Knowing how programs actually work is critical, and makes the process easier to navigate. It is okay to ask questions. It is important to do the research and be proactive.



Plan My Move (<http://planmymove.militaryonesource.mil>) is an online tool that helps service members and their families organize their moves. By providing current duty station, future duty station, and moving date, Plan My Move generates a three-month calendar with general and installation-specific information related to military moves.

Advanced planning includes	
✓	contacting the installation Relocation Assistance Program (RAP) for information and resources regarding the moving process
✓	connecting with the current and prospective installation EFMP family support offices for information and services
✓	gathering information about the prospective community to locate potential sources for support
✓	considering potential legal and financial changes that may occur, including qualification for public benefits
✓	linking with comparable medical and other support services at the new location and preparing for changes in services as they can vary
✓	contacting the SSA office regarding the impact of relocation on public benefits
✓	requesting copies of medical, dental, educational, mental health, or other records
✓	assembling an ample supply of medications or other supplies for use during the transition (a one-month supply is recommended for a domestic move and a three-month supply for an international move)
✓	collecting other special needs items to hand-carry to the new location—be sure to include medical equipment, assistive technology devices, and backup supplies of required items

Overseas Screening

Before being approved to relocate overseas at government expense and with command sponsorship, family members are required to undergo a mandatory screening for overseas suitability, whether or not they are enrolled in the EFMP. The overseas screening process allows each Service to identify medical or educational needs that may exist, and determine if they can be supported at the overseas location. If a special need is identified during screening and the service member is not enrolled in the EFMP, the service member will be referred for enrollment. This may delay approval for the overseas assignment.

The screening process involves the sponsor's personnel and medical commands. An effective overseas screening can help prevent problems that may impact readiness or exacerbate an illness or disability. To ensure that the overseas screening is effective, it is important to openly discuss any conditions, treatments, or concerns with the medical staff. Each Service has a system to screen families

Resiliency is an ongoing process that requires time and effort. It engages people in a step-by-step process. *The Road to Resilience: Tips for Rebounding From Adversity* can be a helpful resource (www.apa.org/helpcenter/road-resilience.aspx).

so that any special needs will be identified and taken into consideration as the service member is assigned to a new duty station:

- Army – Family Member Deployment Screening
- Marine Corps – Suitability Screening
- Navy – Suitability Screening
- Air Force – Family Member Relocation Clearance Process

Living Overseas While Managing a Special Need

Moving overseas creates opportunities to experience different cultures and environments. Some adaptation and adjustment to life abroad is normal, but the challenges may be compounded when managing an illness or disability.

Knowledge of the local laws, norms, and customs can be helpful to prepare for living with a disability in a new culture. For example, host countries may not have requirements for providing public accommodations such as wheelchair access to buildings and walkways. Despite some challenges, with advance planning, living overseas can be an enriching experience.

Building Resilience

Experiencing a serious illness or injury is stressful, and concerns about one's future and quality of life, as well as worries about the impact on family roles and responsibilities, are common. Dealing with the stress of an illness or injury can lead to feelings of frustration, isolation, and resentment.

Resilience is the ability to adapt in the face of a setback or challenge such as a serious illness, injury, or other significant sources of stress. It involves harnessing inner strength to maintain flexibility and balance in life while dealing with stressful circumstances. It is not about being tough and going it alone; being able to reach out and ask for help is one of the keys to resilience.

Resilience won't make problems go away but it can provide the ability to move forward, find enjoyment in life and handle current and future stress better. Resilience involves behaviors, thoughts, and actions that are learned; it is not simply a trait that people either have or do not have.

A combination of factors contributes to resilience. First, a primary factor is having caring and supportive relationships that provide role models and offer encouragement and reassurance. Another factor is having realistic expectations about treatment, goals, and what activities can and cannot be accomplished. It is important to maintaining a positive outlook. People feel more empowered ([see Life Domains Addendum, A:7](#)) and positive about the future if they are the ones determining what things can be controlled and what cannot.

Additional factors associated with resilience include:

- a positive self-perception and confidence in strengths and abilities
- skills in communication and problem solving
- trying to make every day meaningful
- learning from experience
- remaining hopeful
- taking care of oneself
- being proactive
- the capacity to manage strong feelings and impulses

Applying these strategies, combined with the support of strong relationships and outside assistance, enables individuals facing tough situations to go forward with hope and optimism.

"It is important to realize that you will run into a lot of unknowns."
— Mike, caregiver

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Notes

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Educational Paths

Individuals can take several paths to obtain advanced education. The right path depends on the individual's interests, talents, and goals. High schools can offer a variety of training options besides the traditional 'college bound' courses.

High School Opportunities for Trade and Career Technical Education

Career technical education (CTE) programs focus on developing practical career skills by providing classroom and actual hands-on training. These programs are available in most public school systems through the local or regional CTE centers. High school students can earn academic credits (e.g., mathematics, science) while gaining skills and competencies in trade and technical courses, such as:

- graphic design
- cosmetology
- welding
- auto mechanics
- marketing
- agriculture
- child care
- health care

Students participating in these programs earn skill certificates that are recognized by employers, community colleges, and trade unions. Many of these programs offer matriculation agreements so that students can move seamlessly into community or four-year colleges to continue and complete their academic and skill training.

Other High School Program Options

In an effort to provide real-world work experience, some states have begun offering employment or career readiness programs to youths with special needs who are moving into the adult world.

Addendum

High School/High Tech Program

The High School/High Tech Program (HS/HT) (www.dol.gov/odep/programs/high.htm) provides students with special needs the opportunity to explore careers in science, mathematics, and technology. HS/HT sites feature:

- career assessment and awareness, as well as work-readiness skills
- connecting to services and activities that support the student, such as tutoring to improve academic performance, assistive technology to address accommodation needs, mentoring, and transportation
- work-based experiences that include site visits, job shadowing, internships, entrepreneurial ventures, and paid employment
- development and leadership activities, which can include support, independent decision-making skills, service learning, and self-determination and self-advocacy skills

Project SEARCH

The Project SEARCH (www.projectsearch.us) High School Transition Program provides students with special needs real-life work experience, employment and independent living skills, training and career exploration, and job coaching to help in the transition from high school to the adult world. Project SEARCH serves students with significant developmental/intellectual disabilities who are in the last year of their educational program. Most participants are eligible for vocational rehabilitation as well as resources through the local or state Developmental Disability agencies.

Start on Success

Start on Success (www.nod.org—search "start on success") is a program that offers students with special needs an introduction to workplaces and helps them learn work behaviors and skills that promote independence and self-sufficiency. The program also allows employers to learn what participating youth can contribute to the employment sector. Start on Success students spend part of each day working in paid, entry-level positions in large community businesses—typically hospitals, universities, or other organizations that offer a variety of professional positions. Students may spend the remainder of their day receiving academic instruction to earn their diploma. Students' skills, interests, and future career goals are matched to specific work sites, where supervisors serve as mentors and provide guidance and support.

Final Care

After an individual passes away, there is no immediate need to hurry into making funeral arrangements. Family and friends that are present may wish to sit, talk, meditate, pray, or say goodbye. When they are ready, they can begin with the implementation of the final instructions. The hospice care nurse may be available to help the family with this process. In general, the steps taken regarding the funeral process are:

- Call the appropriate authorities if the person has passed away in the home so that a legal pronouncement of death can be made. Depending on the locality, this may be done by the Hospice Care nurse, family doctor, coroner, or funeral home.
- Arrange for organ donation, if appropriate.
- Ensure that appropriate emotional support is available to those affected.
- Make arrangements for the care of any children or animals in the home.
- Review the final instructions regarding funeral and burial arrangements.
- Contact the funeral home to make final arrangements. The funeral director will take care of transporting the body, making logistical arrangements, obtaining certified copies of the death certificate, and placing obituary notices. They may also assist in filling out claims forms for Social Security survivor benefits, veteran benefits, or life insurance claims.
- Notify family, friends, employer, and clergy of the death.
- Attend the final arrangements.
- Provide support to others; seek assistance if help is needed with dealing with the grief.
- Gather important estate planning documents, including at least ten copies of the death certificate.
- Contact the individual's executor of the estate or an estate planning attorney to file for probate and discuss estate matters.
- Investigate any insurance or employee benefits available and make proper notifications.
- Notify business, financial organizations, agencies, and other important organizations of the death.

For more information on recruiting a professional caregiver, view the publication *Working Successfully with In-Home Care Providers* (extension. oregonstate.edu — search on the publication title).

Home Care Provider Considerations

When hiring a home care provider, it is important to determine if the person is suited to the position. A description of the essential routines, daily activities, and position expectations must be thoroughly discussed with any potential providers. Compatibility between the potential provider, the care receiver, and the family must also be determined to ensure a successful and harmonious caregiving environment.

If the applicant appears to meet the requirements, contact the references to ensure the person can perform the duties and is reliable. Be sure to inquire about the person's strengths and limitations, and why the person left his/her previous position. It is also important to conduct a criminal background check and driving record check, review results of any checks the agency has conducted, and review at least two references before hiring a professional caregiver.

Some questions to ask the potential provider may include

?	What is their work experience in caregiving (or similar area)?
?	Why are they interested in working with individuals with special needs?
?	What about this position interests them?
?	How would they describe themselves?
?	What areas are their strengths?
?	What areas do they find the most challenging?
?	What experiences have they had which will help them do this work?
?	Can they provide references from previous caregiving employment?
?	What specific skills do they bring to this position?
?	Can they describe their training and how it relates to this position?
?	What days and times are they available and how many hours are they expecting?

Some questions to ask the potential provider may include

- | | |
|---|---|
| ? | Are they available for additional duties or in an emergency? |
| ? | What do they see as a typical day being like in this position? |
| ? | How would they handle the difficulty of...? |
| ? | What are their expectations of this position? |
| ? | Are there any duties they cannot perform or are uncomfortable performing? |
| ? | What skills and knowledge do they have regarding medical issues or emergencies? |
| ? | What certifications do they hold? |
| ? | What training will they need to acquire the skills to do this job? |
| ? | What knowledge do they have specific to the illness or disability? |
| ? | Are there any activities they enjoy sharing with their clients? |
| ? | Do they understand that once hired, the individual's schedule is the priority? |
| ? | Do they understand the salary? |
| ? | Do they mind traveling as part of the caregiving employment? |

Legal Process

Every state has its own legal process for determining incapacity and appointing a guardian or conservator. The major procedural steps followed in most states are:

1. A petition is filed with the appropriate court located in the county or district of residence.
2. The court or the petitioner notifies relatives that a petition has been filed.
3. The court appoints a court visitor/investigator and/or a guardian ad litem/attorney to represent the individual and his/her interests.
4. A hearing is held where the judge determines if there is evidence of incapacitation and if the person asking for guardianship is qualified.
5. The court appoints a guardian and/or conservator or denies the request. If appointed, the court defines the nature of the guardianship and the duties of the guardian.

The person being evaluated has the right to attend the hearing, to have legal representation, to see and hear all of the evidence regarding his/her condition, and to present evidence or cross-examine witnesses. The court will likely appoint a guardian ad litem to litigate on the individual's behalf. They may carry out an independent investigation of the facts and circumstances surrounding the issues to protect the individual's interests. The guardian ad litem often interviews people who are important in the individual's life and may visit the home to ensure it is a healthy environment.

During the hearing, the judge will seek to determine if criteria for incapacitation has been met and to what degree. At the end of the incapacitation hearing, the judge may enter a decision and name a guardian and/or conservator or choose to review the evidence and issue a decision later.

If the court makes the decision that full or partial guardianship is required, the judge will appoint a guardian of the person and/or the property. The appointed guardian of the person makes decisions about the individual's life and well-being and, if a conservator has not been appointed, will have limited authority over the individual's finances and property. The court may also appoint a conservator to make decisions regarding the finances and property. The same person can be both guardian and conservator or there may be a different person for each responsibility.

Depending on the circumstances, the court can order a guardianship or conservatorship to be full, limited, partial, or temporary. A guardianship or conservatorship defined as limited or partial restricts the powers of the guardian or conservator and allows the individual to retain more of his/her own legal rights.

Life Domains

Life domains provide a model of thinking comprehensively about the many components of a well-rounded and fulfilling life. By assessing an individual's competencies in each domain, it is possible to identify strengths, interests, preferences, and needs. The life domains overlap and are integral to the themes covered in the Guide for Adults with Special Needs, and include:

- self-determination
- personal responsibility and relationships
- home and family
- education and employment
- physical and emotional health
- community involvement
- recreation and leisure

Self-determination is the principle that every adult has the right to make decisions regarding his/her life. It is key to achieving individual goals within each life domain. To make the principle of self-determination a reality, individuals and their caregivers can follow a process for moving towards self-determination which includes:

- knowing and valuing oneself
- identifying goals and planning how to meet those goals
- taking action and following through on plans to meet goals
- continuing to learn as part of the ongoing self-determination and development process

Note: To enhance self-determination for family members with special needs, caregivers may:

- ask them how to best communicate
- ensure that they hear the person's words and meaning, and are not imposing their own points of view or opinions
- ask themselves if they are committed to helping the person reach his/her full potential
- encourage risk-taking and decreasing dependence of the individual
- teach a process for making decisions and solving problems
- help the individuals become self-advocates

For additional information about self-determination, visit the Helen Keller National Center (www.hknc.org).

Self-Determination and Life Domains



Cronin, M.E. & Patton, J.R. (1993). *Life Skills instruction for all students with special needs: A practical guide for integrating real-life content into the curriculum*. p. 13 Austin TX: PRO-ED.

Personal Responsibility and Relationships

The domain of personal responsibility and relationships includes any activity that adults have to perform, for example, doing daily chores, shopping for groceries, managing money, caring for personal belongings, etc. Personal, community, and professional relationships include interacting with community members, neighbors, service providers, and support professionals on a daily basis.

Home and Family

The home and family domain encompasses caring for the home and those who live within it. Tasks such as maintaining the home, cooking, cleaning, making small repairs, and looking after children or other dependents are part of this domain. Hiring and working effectively with personal care attendants or assistive technology equipment may also be necessary.

Education and Employment

The domain of education and employment provides opportunities to explore employment preferences, options, and benefits. Workplace skills such as timeliness, appropriate interactions with other employees, and consistent attendance are critical. Developing a good transportation plan for commuting is essential.

Physical and Emotional Health

The physical and emotional health domain is essential for adults with special needs to achieve their life goals. To achieve independence, individuals must be able to manage medication, medical and dental appointments, and, in general, look after their own physical and emotional needs.

Community Involvement

The domain of community involvement encompasses an individual's engagement in daily community life, such as participating in neighborhood activities, civic responsibilities such as voting, or involvement in spiritual activities. Being able to understand boundaries and respect others' property and personal limits is crucial to successful community engagement. Emergency planning is another important aspect of community living for both personal safety and emergency preparedness. Access to public or private transportation options allows for participation in most activities within a community.

Recreation and Leisure

An area that is often overlooked is the recreation and leisure domain, which is critical for both social involvement and maintaining good health. It is important that individuals find activities that are enjoyable and of interest to them. Recreation and leisure provide an individual the opportunity to engage in social settings and meet new people or potential friends and often has both physical and mental health benefits.

Safety and Accident Prevention

Accidents or emergencies can often be prevented. When assessing a home for safety, consider these questions:

Safety Questions	
?	Is there adequate lighting in the entry, living areas, and on stairs?
?	Are there nightlights in the bedroom and bathroom?
?	Have all tripping hazards, such as clutter, cords, carpet, or rugs, been removed?
?	Are carpets and rugs secure or slip-resistant?
?	Are electrical cords out from under furniture or carpets?
?	Are electrical outlets used correctly and not overloaded?
?	Are stairs object-free and well lit, with properly secured, slip-resistant handrails?
?	Is the hot water heater set at a safe temperature?
?	Does the bath or shower have non-skid surfaces, grab bars, and seating?
?	Are fire extinguishers accessible and in working order?
?	Have smoke and carbon-monoxide detectors been installed on all levels of the house?
?	Do the exterior doors have peepholes that can be reached?
?	Are emergency numbers posted near the phone?
?	Are entrances and exits clear and accessible?
?	Is the outside of the home free of debris?
?	Are there motion-activated lights on the exterior of the home?



Notes



Notes

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